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YOUNG PEOPLE'S BELIEFS ABOUT HELP-SEEKING
FOR FIRST EPISODE PSYCHOSIS

Section A: How Do Young People's and their Families' Beliefs Affect Help-seeking for First Episode Psychosis? A Review of the Literature.

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OCTOBER 2012

DEPARTMENT OF APPLIED PSYCHOLOGY
CANTERBURY CHRIST CHURCH UNIVERSITY

DECLARATION FOR MAJOR RESEARCH PROJECT

Candidate name: HELEN GLOSSOP

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed (candidate)

Date

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Signed (supervisor)

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STATEMENT 2

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Date

Acknowledgments

Firstly, I would like to thank those that participated in this study. Their stories and resilience were inspirational, and I feel privileged that they agreed to be interviewed for this research.

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Summary of portfolio

Section A evaluates the literature which addresses young people and their families' beliefs about accessing professional help for a first episode of psychosis. Knowledge and beliefs regarding mental health difficulties, and stigma, as well as beliefs about services are found to influence whether help is accessed. Limitations of the current literature are outlined and further investigation is recommended regarding young people's beliefs about help-seeking for psychosis.

Section B presents the findings of a grounded theory study exploring beliefs about help-seeking in young people who have experienced a first episode of psychosis. Five categories of beliefs were identified which contributed to the development of a preliminary model of beliefs about a need for help-seeking. Clinical implications, ideas for future research, and limitations of the study are discussed.

Section C provides a critical reflection of the research project by addressing four questions relating to: research skills acquired; what could be done differently if repeating the study; clinical consequences of the study; and future research projects.

Contents

Declaration	1
Acknowledgements.....	2
Summary of MRP Portfolio	3
Contents	4
List of Tables	8
List of Figures	8
List of Appendices	9

SECTION A: Literature Review

Abstract	2
1. Introduction.....	3
1.1 Psychosis	3
1.2 Help-seeking.....	4
1.3 Early Intervention for Psychosis	4
1.4 Models of Help-seeking	6
1.4.1 Filter Model (Goldberg & Huxley, 1980)	6
1.4.2 Behavioural Model (Andersen, 1995)	8
1.4.3 Network Episode Model (Pescosolido, 1991, 1992)	10
1.4.4 Rickwood et al. (2005)	11
1.5 Summary and Aims	11
2. Review	12
2.1 Knowledge and beliefs regarding mental health difficulties	12
2.1.1 Young people in the general population.....	12
2.1.2 Young people experiencing psychosis	13
2.1.3 Families of young people experiencing psychosis	14
2.2 Stigma.....	16
2.2.1 Stigma and people experiencing psychosis.....	17
2.2.2 Family studies of stigma with young people experiencing psychosis	17
2.3 Beliefs about help-seeking	18
2.3.1 Young people experiencing psychosis	19
2.3.2 Family beliefs	20
2.3.3 Summary of beliefs towards help-seeking	22
3. Limitations and Implications for Further Research	22
4. Implications for Clinical Psychology	24
5. Conclusion	24
6. References.....	26

SECTION B: Empirical Paper

Abstract	2
1. Introduction.....	3
1.1 First-episode Psychosis and Early Intervention Services	4
1.2 Help-seeking.....	4
1.3 Rationale for the Present Study	7
1.4 Research Questions.....	8
2. Methodology	8
2.1 Design.....	8
2.2 Participants	9
2.3 Ethical Considerations	10
2.4 Procedure.....	10
2.5 Data Analysis.....	11
2.6 Quality Assurance Checks.....	11
3. Results.....	12
3.1 Summary of the Model	12
3.1.1 Beliefs that experiences are normal or abnormal	16
3.1.1.1 Inhibiting factors	16
3.1.1.2 Promoting factors.....	17
3.1.2 Perceptions of others beliefs about experiences as normal or abnormal.....	19
3.1.2.1 Inhibiting factors	20
3.1.2.2 Promoting factors.....	20
3.1.3 Beliefs about the process of help-seeking	
3.1.3.1 Inhibiting factors	22
3.1.3.2 Promoting factors.....	22
3.1.4 Beliefs about the outcome of help-seeking	24
3.1.1.1 Inhibiting factors	24

3.1.1.2 Promoting factors	26
3.1.5 Perceptions of others' beliefs about the outcome of help-seeking	28
3.1.1.1 Inhibiting factors	28
3.1.1.2 Promoting factors	29
3.1.6 Existing beliefs about mental health difficulties	29
3.1.1.1 Inhibiting factors	29
3.1.1.2 Promoting factors	30
3.1.7 Beliefs about the impact of experiences on the self	31
4. Discussion	33
4.1 Links to Previous Research and Theory	33
4.1.1 Awareness of difficulties	33
4.1.2 Self-stigma	34
4.1.3 Willingness to seek help	35
4.1.4 Social networks	36
4.2 Clinical Implications	36
4.3 Limitations	37
4.4 Future Research	38
4.5 Conclusion	38
5. References	40

SECTION C: Critical Appraisal

Critical Appraisal	1
What I learnt during this project	2
What would I do differently and why	2
Impact on my clinical practice	4
Further research in this area	6
References	7

List of Tables

Section B

Table 1: Participant demographic information	9
Table 2: Categories and sub-categories of young people's beliefs.....	14

List of Figures

Section A

Figure 1: Filter Model of pathways to psychiatric care (Goldberg & Huxley, 1980).....	7
Figure 2: Population characteristics and health behaviour aspects of Andersen's behavioural model (1995).....	9

Section B

Figure 1: Model of beliefs about help-seeking.....	13
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SECTION D: Appendices

Appendix 1: Search strategy	1
Appendix 2: Flow chart of studies selected for the review.....	2
Appendix 3: Participant information sheet	8
Appendix 4: Consent form.....	10
Appendix 5: Initial interview schedule	11
Appendix 6: Approval letter from NHS ethics committee	12
Appendix 7: Trust Research and Development approval	13
Appendix 8: Abridged research diary	14
Appendix 9: Example of uncoded interview transcript	18
Appendix 10: Table of sub-categories, categories and focused codes.....	19
Appendix 11: Example quotes for one category.....	24
Appendix 12: Samples of coding memos	42
Appendix 13: Early model formation	45
Appendix 14: Publication guidelines for Journal of Mental Health	47
Appendix 15: Letter and project summary of research for Research Ethics Committee	50

MAJOR RESEARCH PROJECT

SECTION A: LITERATURE REVIEW

How Do Young People's and their Families' Beliefs Affect Help-seeking for First Episode Psychosis? A Review of the Literature.

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Abstract

Aim: The importance of early intervention for individuals experiencing psychosis is well understood. Despite this there are still delays in young people accessing services. Beliefs regarding mental health and services are predicted to influence an individual's help-seeking. This review evaluates the literature which addresses whether and how beliefs affect young people and their families accessing professional help for a first episode of psychosis (FEP).

Method: COCHRANE database of systematic reviews, PsychInfo, Medline, CINAHL, and ScienceDirect were searched for peer-reviewed publications using terms relating to FEP and help-seeking. References and citations of relevant articles were searched for further relevant studies.

Results: Of 17 studies selected for review, findings were grouped in to three categories, depending on whether they were relevant to: 1) Knowledge and beliefs regarding mental health difficulties; 2) Beliefs about stigma; and 3) Beliefs about help-seeking.

Conclusion: Knowledge and beliefs regarding mental health difficulties, and stigma, as well as beliefs about services influence whether help is accessed for FEP. Further research is required regarding young people's beliefs about help-seeking, how a young person's own beliefs contribute to a situation where professional help is sought, and how the beliefs of important others influence beliefs about help-seeking.

1. Introduction

Research suggests that accessing professional help early is beneficial for individuals experiencing mental health difficulties (MHDs; McGorry, Purcell, Hickie & Jorm, 2007). The fastest growing evidence base has been for early intervention at the first onset of psychosis (French, Smith, Shiers, Reed & Rayne, 2010). Despite the distress felt by many young people and their families in the early stages of psychosis, a considerable amount of time often elapses before help is sought from professional services (Brunet & Birchwood, 2010). Research indicates that the knowledge and beliefs that young people and their families have regarding experiences of psychosis and help-seeking are important in determining whether and how they access services (Cadario et al., 2011; Tanskanen et al., 2011). This paper reviews and evaluates these studies. Firstly, descriptions of psychosis and help-seeking will be given, followed by an outline of the early intervention for psychosis approach and models of help-seeking. Relevant literature concerning young people and their families' beliefs regarding psychosis and help-seeking will then be reviewed. Finally, clinical and research implications will be considered.

1.1 Psychosis

Psychosis is characterised within mental health services as a distortion in perceptions during which an individual is considered to be to some extent out of touch with reality (Bentall, 2011). Experiences most commonly consist of the presence of hallucinations or delusions, but also include disorganised behaviour, thought and speech (Dunkley, Bates, Foulds, & Fitzgerald, 2007). These experiences have traditionally been associated with psychiatric diagnoses such as schizophrenia, and bipolar disorder, however, psychosis is increasingly being considered as existing on a continuum with normal experiences (van Os, 2003).

First-episode psychosis refers to the initial onset of psychotic experiences, with 80 per cent of people experiencing their first episode between the ages of 16 and 30 (World Health Organisation, 2004). It is estimated that one in 200 people per year in the UK experience psychosis (McManus, Meltzer, Brugha, Bebbington, & Jenkins, 2009).

1.2 Help-seeking

Young people may seek various forms of help for distress associated with psychosis. There are no agreed definitions of help-seeking in the literature, however, the term generally refers to formal support. Rickwood, Deane, Wilson and Ciarrochi (2005) define help-seeking as, “communicating with other people to obtain help in terms of understanding, advice, information, treatment, and general support in response to a problem or distressing experience” (p. 4). As such, help-seeking within this review will be considered as approaching professional health, mental health, or emergency services for understanding, advice, information, treatment or support with MHDs.

1.3 Early Intervention for Psychosis

The effects of delays in treatment for the first episode of psychosis (FEP) have been well documented. For example, a UK study of 253 first episode patients showed that those who waited over one year before receiving help from psychiatric services were three times more likely to relapse during the subsequent two years than those who had sought help earlier (Johnstone et al., 1986). Later entry to treatment leaves young people at higher risk of self-harm (Harvey et al., 2008) and is related to increased suicide risk in those with psychosis (Melle et al., 2006). Two meta-analyses concluded that a longer duration of untreated psychosis was correlated with a number of negative outcomes such as a greater number of overall symptoms, worse overall functioning, and reduced quality of life (Marshall et al.,

2005; Perkins, Gu, Boteva, & Lieberman, 2005). Consistent with this empirical evidence, Birchwood, McGorry, and Jackson (1997) proposed that long term outcomes for those experiencing psychosis may be improved if treatment is received during a three to five year ‘critical period’ following the first episode.

Subsequently, the last 15 years have seen increased investment in early intervention services for young people with psychosis, including approximately 145 services across the UK (Bird et al., 2010). The aim of these services is to identify symptoms earlier and improve access to effective treatment (McGorry et al., 2007). A recent systematic review of EIP services suggested that they have been successful in reducing hospital admission, relapse rates and symptom severity, while improving access to and engagement with a range of treatments (Bird et al., 2010). A London-based randomised control trial found that individuals who accessed EIP services demonstrated increased engagement in establishing social relationships and in educational and vocational pursuits, compared to people receiving treatment as usual (Garety et al., 2006).

Despite the reported success in supporting young people with psychosis, it appears that there is still a delay in young people reaching early intervention services (Brunet & Birchwood, 2010). Developing knowledge of help-seeking processes is important to ensure that the maximum number of individuals possible can access support during their FEP. Firstly this requires an understanding of the factors that can lead to delays between initial experiences of psychosis and the initiation of help-seeking (Brunet, Birchwood, Lester & Thornhill, 2007).

1.4 Models of Help-seeking

Help-seeking for MHDs is a complex process involving a number of individual, interpersonal, cultural, and psychological factors (Wilson, Bushnell, & Caputi, 2011). Different theoretical models have been applied to explain how professional help for MHDs is accessed (Ajzen & Fishbein, 1980; Goldberg and Huxley, 1980; Andersen, 1995). Three dominant models are selected for discussion due to their prominence in the literature and their relevance to decisions about help-seeking. A specific theory of the factors affecting young people's help-seeking for MHDs will also be introduced and critiqued. It will be argued that it is important to understand how a 'need' for help is perceived by young people with psychosis, with consideration given to how and whether social networks influence young people's beliefs about help-seeking.

1.4.1 Filter Model (Goldberg & Huxley, 1980).

Goldberg and Huxley (1980) describe a framework whereby people can access help at five different levels, and must pass through "filters" in order to obtain appropriate help at each level (Figure 1). Filters include the individual's decision to seek help, the recognition of MHDs by a primary care provider, and the provider's decision to refer the individual to specialised care, be that community or inpatient care. Most relevant to help-seeking is movement from level one, "mental illness in the community", to level two, "attending primary care" through the first filter "the decision to seek help".

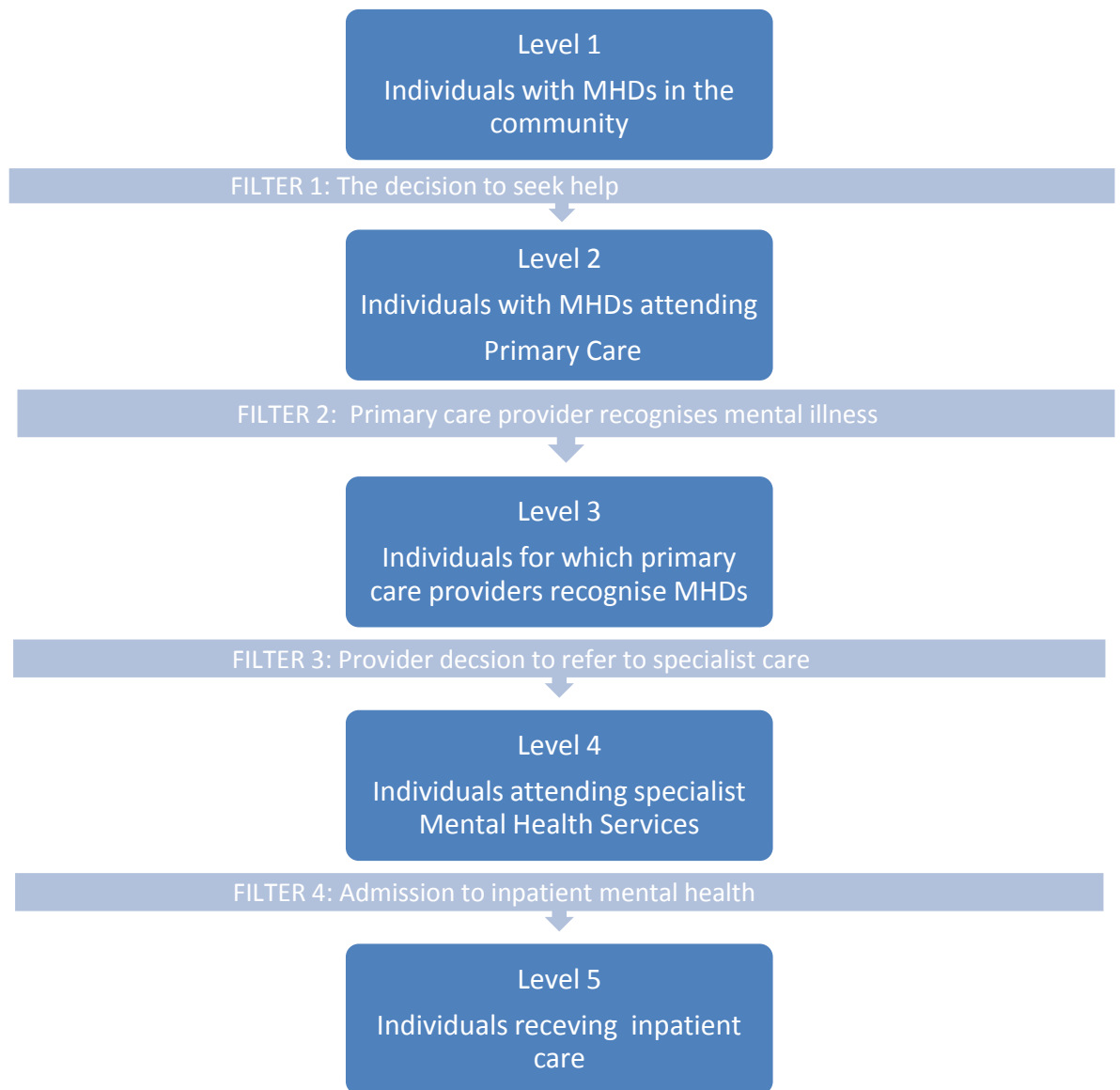


Figure 1. Filter model of pathways to psychiatric care (Goldberg & Huxley, 1980)

Variables hypothesised to influence the decision to seek help in this model are illness recognition, symptom severity, and degree of psychological distress. Social factors are also considered, and it is suggested that an individual may seek “provisional validation” from significant others that they are “sick”. It is argued that individuals experiencing psychosis will pass through each filter more rapidly than those with other MHDs. However, this assumption is not upheld by more recent findings which suggest that 12 per cent of young people experiencing a FEP wait three years or more before receiving care (Norman, Malla,

Verdi, Hassall, & Fazekas, 2004). This model can also be criticised as leading people in to a role of being “sick” in comparison to current psychological approaches which focus on normalising young people’s experiences of psychosis (Bentall, 2011).

1.4.2 Behavioural Model (Andersen, 1995).

Other models focus on the point at which an individual seeks help, the only stage of the Goldberg and Huxley (1980) model at which help-seeking is the function of an individual and not the service provider. Andersen’s behavioural model of access to health care (Andersen, 1995; revised from Andersen & Newman, 1973) proposes that service use is a function of: 1) an individual’s predisposition to using services; 2) factors that enable use; and 3) the individual’s “need” for a service (Figure 2).

Predisposition factors may include age, gender and health beliefs. Beliefs include the attitudes, values, and knowledge held about MHDs and services. Andersen (1995) differentiates between community enabling resources (e.g. there must be services available for individuals to access) and personal enabling resources (e.g. ability and income to travel to services). “Need” for a service is defined as a combination of the extent to which both the individual and a professional perceive that help is required. Therefore understanding the perception of need from an individual will improve our understanding of help-seeking. However, where a need for help is perceived by a professional but not the individual with a MHD, they may be fast tracked into the health system without formally seeking help (Andersen, 1995).

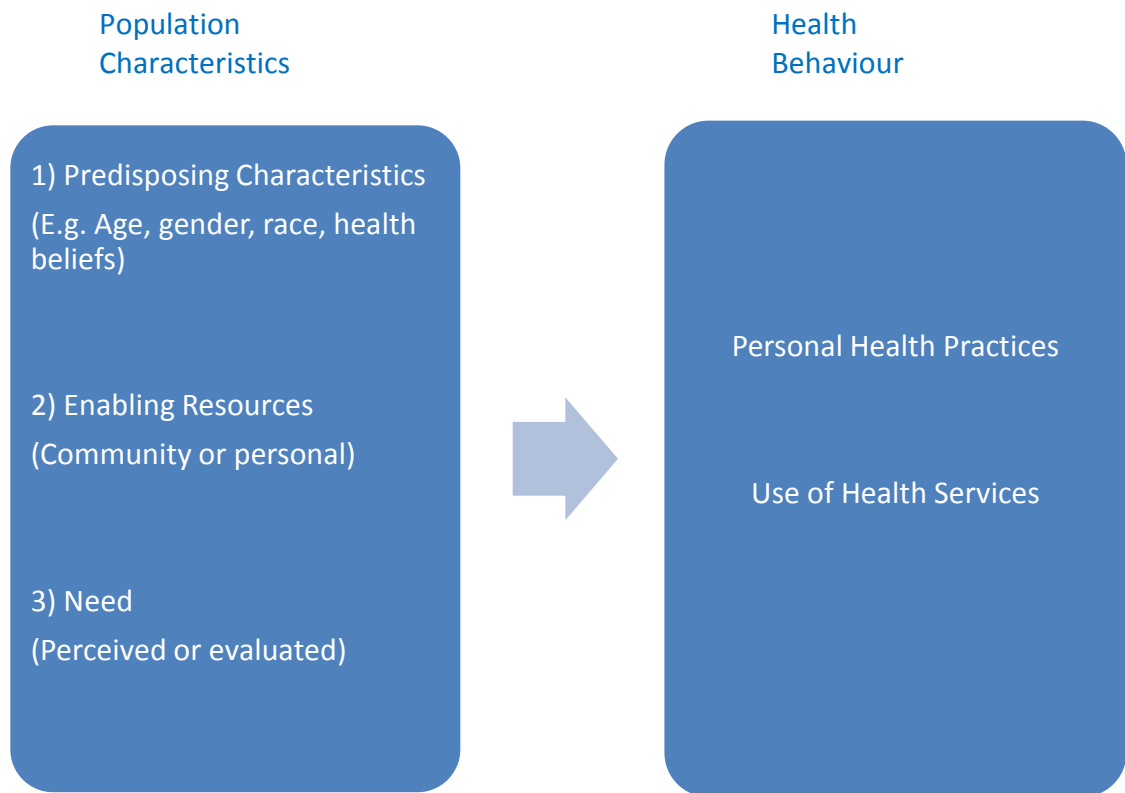


Figure 2. Population characteristics and health behaviour aspects of Andersen's behavioural model (1995).

Investigations of help-seeking for psychosis have focused on the pre-disposing factors of the behavioural model such as gender, socio-economic status and ethnicity that influence quantifiable periods of untreated psychosis (Platz et al., 2006). A recent review found that studies are inconsistent in their findings regarding the impact of gender, socioeconomic status, and ethnicity on treatment pathways (Anderson et al., 2010). For example, one study found that ethnicity and access to services through emergency services or involuntary admission was mediated by being male (Morgan et al., 2005) while another found ethnic differences for females only (Harrison et al., 1989). Another review focused on additional predictive variables including the type of symptoms experienced and whether family

members were involved in help-seeking (Compton & Broussard, 2011). Variables of the behavioural model that remain less understood are beliefs regarding help-seeking and young people's perceived "need" of when help is necessary for experiences of psychosis.

1.4.3 Network Episode Model (Pescosolido, 1991, 1992)

The models discussed have been criticised for being overly deterministic and creating a rigid profile of individuals, based on discrete characteristics such as age or gender, to predict professional help-seeking (Biddle, Donovan, Sharp, & Gunnell, 2007). However, others have attempted to conceptualise professional help-seeking as a dynamic process that takes place within a socially interactive context. One such approach is the Network Episode Model (NEM; Pescosolido, 1991, 1992). Social networks are considered to include an individual's social supports (i.e. family and friends) but also wider organisations that impact on care. Individuals and these networks are regarded as interdependent. Interaction with these broad networks creates beliefs (e.g. through what friends, family, and organisations say cause MHDs), information (e.g. where one can obtain help for difficulties), and subsequent action scripts (e.g. whether or not to seek care from professionals; Pescosolido, 2011). Social networks not only socially influence an individual's behaviour. The cultural beliefs of the network, regarding what may effectively reduce the distress of MHDs, also determines whether the individual will access help.

The NEM (Pescosolido, 1991, 1992) seems particularly helpful in understanding help-seeking for psychosis which is often described as more 'other defined' than alternative types of MHDs. This is because other people may perceive a problem when the young person does not, and subsequently initiate help-seeking or support the individual experiencing difficulties in accessing care (Morgan et al., 2005). These findings are consistent with research

suggesting that those who are more socially withdrawn (as often seen in the initial stages of psychosis) are less likely to access professional help (Bechard-Evans et al., 2007).

Furthermore, it may be especially likely that family and friends will be involved in initiating support for younger people.

1.4.4 Rickwood et al. (2005) theory of young people's help-seeking

Rickwood et al. (2005) conceptualise young people's help-seeking for MHDs as a process whereby the personal becomes increasingly interpersonal. This begins with an awareness of difficulties and an appraisal that help is needed. Young people must then be able to articulate difficulties to others, and sources of help must be available. Finally, the young person must be willing to seek out and disclose difficulties. However, help-seeking for psychosis may be different than for other MHDs, such as depression and anxiety, as it has been found to be more stigmatised by society (Crisp, Gelder, Goddard & Meltzer, 2005). Therefore, an understanding is needed of whether these stages are present for young people experiencing psychosis, and how the beliefs of others may be implicated.

1.5 Summary and Aims

A previous review has considered how discrete factors contribute to initial entrance into professional care services for psychosis (Anderson et al., 2010). However, factors beyond 'pre-disposition' determinants need to be considered. Beliefs regarding mental health and services are predicted to influence an individual's access to care (Andersen, 1995). As such, greater detail regarding these beliefs should be included in models of help-seeking. Help-seeking is also affected by the beliefs of significant others, especially in relation to psychosis (Pescosolido, 2011; Morgan et al., 2005). An understanding of the help-seeking

process, from beliefs about difficulties to beliefs about disclosing to others, will enable the targeting of interventions to promote earlier help-seeking (Rickwood et al., 2005). This review will be the first to consider how people's beliefs and the beliefs of those closest in their social networks may impact on help-seeking for early psychosis.

2. Review

Searches were completed using a range of databases (Appendix 1). Combinations of search terms referring to 'help-seeking', 'first episode' and 'psychosis' were used to identify papers. After reviewing 640 abstracts from the search, along with references and citations of relevant articles, 17 papers were selected as specifically relevant to young people's and their families' beliefs about help-seeking for psychosis (Appendix 2). Findings of this review are presented in three categories in this review: knowledge and beliefs regarding MHDs; beliefs about stigma; and beliefs about help-seeking.

2.1 Knowledge and Beliefs Regarding MHDs

Knowledge and beliefs about MHDs that are considered to support their recognition, management, and prevention have been described as "mental health literacy" (Jorm et al., 1997). Well developed mental health literacy is positively associated with help-seeking. This differs from stigma, in which negative discriminatory beliefs are implicated (see section 2.2).

2.1.1 Young people in the general population.

Two Australian studies have explored how mental health literacy may influence help-seeking for psychosis from the perspectives of a general population sample. A large scale telephone survey of 1027 young people aged 12 to 25 assessed abilities in recognising MHDs

as they are clinically defined and identifying the type of help considered appropriate (Wright et al., 2005). Results of a content analysis showed that a quarter of participants were able to identify psychosis from a vignette, in comparison to half the sample who recognised depression. Seeing a psychiatrist or psychologist was suggested as the best form of help for someone experiencing psychosis. Participants were significantly less likely to advise that family and friends would be an appropriate source of support for psychosis compared to depression.

A later study of the same data set found using multiple logistic regression analyses that young people who were able to identify psychosis were less likely to suggest that the person in the vignette should deal with the problem on their own, and more likely to suggest seeking help from an appropriate professional service (Wright, Jorm, Harris, & McGorry, 2007). These studies therefore suggest that educative approaches to raise young people's awareness of psychosis may encourage seeking help from professionals. However, for both these studies it may be questioned whether the findings are predictive of people's actual beliefs and responses towards individuals with psychosis as they present in real world situations. The quantitative survey technique did not allow the researchers to clarify what young people understood by psychological and psychiatric help. In addition, the expectation for young people to identify 'psychosis' within these studies did not allow for the perspective that psychosis may be considered as existing on a continuum with normal experience (Bentall, 2011).

2.1.2 Young people experiencing psychosis.

Studies analysing retrospective accounts of young people with psychosis have found that often they did not initially identify that their experiences may constitute MHDs for which

intervention may be beneficial. In a grounded theory study of 15 young adults in the USA many participants reported being the first person to recognise changes in their thinking, emotions and behaviours (Judge, Estroff, Perkins & Penn, 2008). However, participants expressed that they perceived early changes such as hearing voices as ‘part of who they were’ and reported that they generated meaningful accounts of their experience such as attributing them to stress or life changes. None attributed changes as being indicative of MHDs before receiving a diagnosis (Judge et al., 2008). In a very recent UK study in which 21 young people were interviewed about experiences of early psychosis, a thematic analysis found participants similarly reported a range of responses. Some did not believe they had a problem, some attributed their problems to mental illness, and others attributed their experiences to other factors such as substance misuse, stress, depression or sleep deprivation (Tanskanen et al., 2011). These studies are useful in adding to the scarce literature regarding service-user perspectives as to how individuals may initially understand emerging psychosis and how this can inhibit help-seeking. However, the findings are limited in providing information as to how people move past these beliefs about their experiences to access help from services.

2.1.3 Families of young people experiencing psychosis.

Studies have suggested that, as with the young person themselves, family members may not always conceptualise changes in their relative’s mood or behaviour as indicative of a MHD. A thematic analysis of five parent reports of help-seeking for FEP showed that participants reported uncertainty about initial behavioural changes and typically attributed unusual ideas, changes in functioning and withdrawal to developmental changes that may be considered as common features of adolescence (Czutcha & McCay, 2001). Other studies report that changes in young people were also attributed to causes such as stress, depression, or drug use (Bergner et al., 2008; de Haan, Welborn, MKrikke, & Linszen, 2004).

Families reported that they respected the individual's autonomy and rights to make their own decision to seek help (Bergner et al., 2008). It was assumed that young people would recognise that they were experiencing difficulties, in contrast to the finding that young people often do not (Judge et al., 2008). It should be noted that many young people within this study were between the ages of 18 and 25. Families' beliefs regarding autonomy may be less relevant when onset appears in a younger person.

Two studies have explored experiences of FEP from the perspectives of both adolescents and their parents (Cadario et al., 2011; Tanskanen et al., 2011). Some similarities emerged between young people's attributions regarding their initial experiences and those of their parents, for example relating difficulties to stress or drug use, but there were also differences. Cadario et al. (2011) interviewed 12 young people and 12 carers, and analysed transcripts using a general inductive approach (Thomas, 2006), resulting in a number of themes and categories. They found that while young people were experiencing unusual physical sensations, hallucinations and delusions, and difficulties in thinking, their parents were more likely to notice behavioural changes and somatic symptoms such as loss of appetite or sleep disturbances. Neither group were likely to attribute changes to a MHD. However, the topic guide for this study included specific questions regarding the impact of drugs, alcohol and other stressors which may have biased participants to mention these factors as impacting on behaviour. Nine carers interviewed for the study by Tanskanen et al. (2011) described how a lack of awareness that their relative was experiencing psychosis led to delays in help-seeking. Given the overlap in some beliefs between young people and their families it would be interesting to explore whether young people's perceptions of their relatives' beliefs impact on their own beliefs about their experiences.

In a Brazilian study exploring beliefs about psychosis cross-culturally 15 relatives of young people were interviewed and passages were coded into categories. Family members reported they often sought a spiritual understanding of their relatives' initial experiences of psychosis, for example, that the patient was possessed or their behaviours represented a malign force (Monteiro, dos Santos, & Martin, 2006). This should be taken in the context that spiritual explanations of behaviour are dominant within the Brazilian culture, but may also be relevant to sub-populations of ethnically-diverse UK populations. The authors emphasise the importance of considering that the way in which family members understand changes in behaviours may differ from that of clinicians. However, the authors assert in their introduction that the beliefs of psychiatrists and patients will always differ regarding mental health and require negotiation. It is questionable whether this assumption may have biased their interpretation of the data.

In summary, studies investigating knowledge and beliefs regarding psychosis in young people have found that few individuals in the general population or those experiencing emerging psychosis readily recognised the experiences as a MHD requiring professional intervention (Wright et al., 2005; Wright et al., 2007; Judge et al., 2008). Similarly, family members typically attributed changes in their relatives' behaviour to other factors such as drugs, adolescent behaviour or spiritual forces (Czutcha & McCay, 2001; Bergner et al., 2008; Monteiro et al., 2006). Families reported that a lack of their awareness of psychosis resulted in help-seeking delays (Cardario et al., 2011; Tanskanen et al., 2011).

2.2 Stigma

A wealth of research has indicated that stigma is a significant barrier to accessing mental health services (Thornicroft, 2006). Two types of stigma have been differentiated: public stigma and self-stigma. Public stigma refers to the endorsement by the general population of prejudiced beliefs and discrimination against those with MHDs. Self-stigma refers to the internalisation of public stigma by individuals with MHDs (Corrigan & Watson, 2002). Stigma may lead to the rejection of the possibility of having a MHD, and an associated avoidance of help-seeking in an attempt to preserve self-esteem (Vogel, Wade & Hackler, 2007).

2.2.1 Stigma and people experiencing psychosis.

In a study using Interpretative Phenomenological Analysis to explore stigma experienced by six individuals with psychosis Knight, Wykes, and Hayward (2001) found participants had experienced both public and self-stigma. Individuals spoke of perceived and realised negative attitudes from others, and described a negative self-identity. However, while some participants were experiencing FEP, others had been in contact with services much longer. Perceptions and responses to stigma may vary over time and therefore gaining an understanding of individuals' beliefs about stigma at FEP is important. In addition, this study focused especially on stigma relevant to experiences of psychosis. Further understanding of stigma specifically related to use of services would be informative.

Research exploring stigma as a specific barrier for initial help-seeking for psychosis is limited, although there is evidence that awareness of stigma is evident from the early stages of psychosis. For example, Judge et al. (2008) found that initially participants not only avoided professional help due to an awareness of stigma but also found it difficult to describe

their experiences to lay individuals in a way that would not expose them as “crazy”. Young people report that they are more likely to avoid using services if they believe others would have a negative reaction to disclosure of unusual experiences (Tanskanen et al., 2011).

2.2.2 Family studies of stigma with young people experiencing psychosis.

The families of those with psychosis also report experiencing stigma. A US grounded theory study reported interview data from 12 relatives of young people with psychosis exploring whether experiences of perceived stigma was a factor in them supporting help-seeking (Franz et al., 2010). Families reported they had experienced negative reactions from others towards their relatives’ increasingly worrying behaviour, and felt reluctant to label their relative as having a MHD because of the negative stereotypes this evoked. Participants in this study were African American families, therefore the extent to which these factors can be generalised to families of other ethnic origins must be questioned. For example, the authors comment that in the USA, stigma of MHDs may be greater amongst black minority groups. This suggestion is supported by a small study of 20 relatives that found using chi-squared analyses that, in comparison to more prominent ethnic groups, ethnic minority families of individuals with recent-onset psychosis endorsed a sense of shame and need to conceal their relatives experiences (Wong et al., 2009). This highlights the importance of exploring perceptions of stigma prior to help-seeking in young people of different backgrounds experiencing FEP.

In summary, there is evidence that people with psychosis experience stigma (Knight et al., 2006; Judge et al., 2008) and initial studies suggest this prevents individuals with FEP seeking help from professional services. Families report their own negative responses (Wong

et al., 2009) and awareness of others' negative reactions to their relatives experiences of psychosis (Franz et al., 2010), which delays help-seeking.

2.3 Beliefs about Help-seeking

In a summary of young people's help-seeking for health and social problems Barker, Olukoya, and Aggleton (2005) emphasise beliefs about a "need" for help as essential to help-seeking from professionals. It is emphasised that there may be inconsistencies between parent perceptions and the perceptions of young people regarding beliefs about a "need" for help.

2.3.1 Beliefs of young people experiencing psychosis.

There is some evidence that young people experiencing psychosis may access support due to an emerging belief that help is needed. Hardy, Dickson, and Morrison (2009) thematically analysed interviews with ten young people with FEP who identified that they accessed services when they perceived a worsening of experiences such as paranoia, hearing voices or fluctuating mood. Therefore for some, at least, there is a move towards help-seeking when a crisis is reached and they believe that professional support may be required. However, for other young people it appears a "need" for help is never realised, and help-seeking is initiated by others without their consent (Tanskanen et al., 2011). It is important to understand what differentiates young people who arrive at a "need" for help, and those who do not.

A qualitative study of eight participants using an interpretive interactionist approach indicated that young people waited many months before they disclosed their experiences to anyone because they did not want to cause anxiety in their family members (Boydell,

Gladstone & Volpe, 2006). A lack of willingness to disclose difficulties may also partially account for family reports of withdrawal (Bergner et al., 2008). Therefore, it appears that young people who lack confidence to disclose about their experiences to others may delay help-seeking. It would be useful to explore how beliefs of family members regarding help-seeking impact on young people's beliefs towards accessing services to further understand how and when approaching professional help occurs.

Two experimental studies have looked at beliefs in the form of health locus of control in relation to help-seeking for psychosis in samples of 47 and 42 young people with FEP respectively (Skeate, Jackson, Birchwood & Jones, 2002; Haley, Drake, Bentall & Lewis, 2002). Individuals with psychosis were more likely to have a lower "internal" health locus of control, and higher "powerful other" health locus of control than normative data or a control group. Therefore individuals with psychosis may feel less personally responsible for their own health and believe that health outcomes are more greatly influenced by other influential people. This is consistent with research suggesting that people experiencing psychosis may place themselves at lower "social rank" than others, which would lead to high compliance with the wishes of important others (Birchwood et al., 2002). However, it could be argued that people who have recently accessed professional services, especially those who have been hospitalised, may be more likely to believe that their health care is determined by the actions of influential others. Unfortunately the measure used (Multidimensional Health Locus of Control Scales; Wallaston, Wallaston & De Vellis, 1978) did not allow for distinction of whether "powerful others" were considered to be those in their social network or professionals. Interestingly, Haley et al. (2002) also found that a greater internal locus of control was significantly correlated with a shorter duration of untreated psychosis, which

suggests that those who believe they are more responsible for their own health are quicker to seek help than those who believe they are less responsible for their beliefs.

2.3.2 Family beliefs.

Corcoran et al. (2007) interviewed 13 family members of young people aged 16-24 regarding their involvement in the help seeking process, and analysed results using a phenomenologically based approach. Families primarily appear to believe that there is a need for professional help-seeking when symptoms of psychosis became visible in young people through behaviour such as shouting or reporting “alarming” experiences (Corcoran et al., 2007). Many families sought help when they believed a young person’s behaviour represented a risk to themselves or others (Bergner et al., 2008). Earlier help-seeking at this time was associated with family members having greater resources including contact with friends, especially if these friends had knowledge of services (Corcoran et al., 2007). Families often sought help at the insistence or recommendation of others in their social network. This emphasises the importance of how the beliefs and perspectives of others in the wider social network may be implicated in help-seeking.

Monteiro et al. (2006) reported that relatives were concerned about using services that were perceived to be “aggressive and authoritarian”. There was also a belief that taking medication and being with others with MHDs may make their relatives’ difficulties worse. No positive connotations of seeking help were reported. Tanskanen et al. (2011) also reported that carers expressed misgivings about services and were worried about treatment. These studies aid understanding of when beliefs of those providing social support may be a barrier to young people seeking professional help. Studies are needed to similarly understand young people’s perceptions towards help-seeking from professionals.

2.3.3 Summary of beliefs towards help-seeking.

Young people sought professional support when they believed that it might be needed (Hardy et al., 2009), although not all young people reached this stage (Tanskanen et al., 2011). Delays in disclosure occurred when individuals believed family members might find their experiences anxiety-provoking (Boydell et al., 2006). Young people who believed that they were more responsible for their own health appeared quicker to seek help. Individuals who accessed services reported greater beliefs that others were responsible for health care, although it was unclear whether this was a response to being in services (Skeate et al., 2002; Haley et al., 2002). Families were most likely to seek help when young people's behaviour appeared risky or others recommended accessing services (Corcoran et al., 2007). Some family members reported fears about mental health services (Monteiro et al., 2006; Tanskanen et al., 2011).

3. Limitations and Implications for Further Research

Research about family members' beliefs appears further developed than that of young people with psychosis themselves. Studies with young people have focused predominantly on beliefs about experiences of emerging psychosis. There are few studies examining young people's beliefs about the importance of accessing help, what they believe services have to offer, and about stigma. There is an important need to represent the accounts of young people with lived experience of using early intervention services. This will provide a valuable alternative to professionally influenced perspectives on factors involved in help-seeking; it will also help to retain the focus on the young people themselves (Knight et al., 2003).

Few studies have considered young people within the context of their social network (Pescosolido, 2011). This may include parents, teachers, or friends (Rickwood et al., 2007).

Further research could consider how young people perceive the beliefs of others within their social network, and how this impacts on their help-seeking. This includes the impact of beliefs of peers for which there is limited research (Boydell, Stasiulis, Volpe & Gladstone, 2010).

Furthermore, the current research regarding access to help for first onset of psychosis has predominantly focused on beliefs that hinder help-seeking. What seems less clear is what factors promote help being sought. One possibility is that individuals do not have the beliefs which act as a barrier to help-seeking, for example, they have good mental health literacy, do not experience developing psychosis as stigmatising, and believe that services may be helpful. However, it could be that there are additional factors present for these people that facilitate seeking professional help. This could include factors such as beliefs about whether professionals can help, or an ease of expressing emotions, (Wilson & Deane., 2001). Given the importance of family members to a young person accessing help for psychosis, these facilitating factors could also be relevant to those that are supporting a young person.

In summary, important areas to explore are:

- Young people's beliefs about help-seeking for psychosis from mental health services.
- Young people's beliefs that facilitate their help-seeking.
- Young people's perspectives on the beliefs of important others towards help-seeking and how these influence their own help-seeking.

4. Implications for Clinical Psychology

Clinical psychologists have an important role in developing Early Intervention services to be more accessible to young people (French et al., 2010). Understanding that young people initially believe psychosis to be part of ‘who they are’ emphasises the usefulness of conceptualising psychosis as being on a continuum with normal experience. This can be used to help young people understand their difficulties in context, while at the same time prompting them to consider seeking help more readily and thereby increasing engagement. Increased knowledge of the impact of stigma on help-seeking can be used to further develop services to be accessible.

Interventions that support the development of knowledge and understanding of young people towards psychosis and help-seeking are needed. This is essential in ensuring young people are able to access appropriate, evidence-based services. A number of projects could address this, ranging from widespread campaigns aimed at the public to educational initiatives targeting specific populations.

5. Conclusion

The importance of early intervention for psychosis is well recognised and of critical importance for young people is the role that their social networks play in the help-seeking process. There is emerging literature examining how beliefs regarding difficulties may impact help-seeking for young people and their families. Research to date has found that knowledge and beliefs regarding MHDs, stigma, and beliefs about services influence whether help is accessed. Further research is required regarding young people’s beliefs about help-seeking, how their beliefs contribute to a situation where professional help is sought, and how the

beliefs of important others influence help-seeking. Understanding these beliefs will aid the design of interventions and services which facilitate young people to seek support.

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MAJOR RESEARCH PROJECT

SECTION B: EMPIRICAL PAPER

Young People's Beliefs about Help-Seeking for First Episode Psychosis

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Abstract

Objectives: The importance of early intervention for positive outcomes following a first episode of psychosis (FEP) is recognised, however, there are still delays in young people seeking help. The aim of this qualitative study was to explore beliefs about help-seeking in young people who have recently experienced a FEP.

Method: Twelve participants were interviewed and transcripts were analysed using grounded theory.

Results: Young people's beliefs about their experiences as normal or abnormal, and about the process and outcome of help-seeking, influenced beliefs about needing help. Existing beliefs about mental health problems, and beliefs about the impact of experiences on the self were important to the meaning young people ascribed to beliefs about help-seeking. Social networks were important in the development of these beliefs.

Conclusion: This study identified beliefs which promoted and inhibited young people's help-seeking beliefs for FEP. Self-stigma was present prior to help-seeking. Implications for clinical interventions include education to promote help-seeking for distress and not abnormality, and to dispel myths about the help-seeking process and outcome. Further research is needed to determine which beliefs are most important to young people's help-seeking for FEP.

1. Introduction

1.1 First-episode Psychosis and Early Intervention Services

First-episode psychosis (FEP) refers to the initial period of psychotic experiences, with 80 per cent of people experiencing their first episode between the ages of 16 and 30 (World Health Organisation, 2004). Negative outcomes, such as low overall functioning and reduced quality of life, associated with a long duration of untreated psychosis, have been well documented (Marshall et al., 2005; Perkins, Gu, Boteva, & Lieberman, 2005). Furthermore, there is evidence that intervention in a three to five year ‘critical period’ after FEP can lead to positive outcomes (Birchwood, McGorry, & Jackson, 1997; Norman et al., 2011). Subsequently, Early Intervention for Psychosis (EIP) services, that aim to identify symptoms earlier and improve access to effective treatment, have grown in the UK and worldwide (French, Smith, Shiers, Reed, & Rayne, 2010). A systematic review of UK EIP services suggested that they have been successful in reducing hospital admission, relapse rates and symptom severity, while improving access to, and engagement with, a range of treatments (Bird et al., 2010).

1.2 Help-seeking

Rickwood, Deane, Wilson and Ciarrochi (2005) define help-seeking for mental health difficulties (MHDs) as “communicating with other people to obtain help in terms of understanding, advice, information, treatment, and general support in response to a problem or distressing experience” (p. 4). Help-seeking is typically understood within the literature as seeking help from formal supports such as professional health, mental health or emergency services.

Despite the reported success of EIP services in supporting young people with psychosis, it appears that there is still a delay in young people reaching services (Brunet & Birchwood, 2010). A number of investigations of help-seeking for psychosis have focused on pre-disposing factors such as gender, socio-economic status and ethnicity as predictors of duration of untreated psychosis in individuals (Drake, Haley, Akhtar & Lewis, 2000; Morgan et al., 2005). However, a recent review showed that the data on pre-disposing factors is inconsistent (Anderson, Fuhrer, & Malla, 2010), and additional complex variants such as types of symptoms, health service factors, and family functioning have also been suggested as important (Compton & Broussand, 2011).

Others have conceptualised professional help-seeking as a process that is bound within a socially interactive context that cannot be reduced to discrete predictive factors. For example, the Network Episode Model (Pescosolido, 1991, 1992) highlights social networks and their associated culture as central in influencing an individual's help-seeking behaviour. This considered, Rickwood et al. (2005) conceptualise young people's help-seeking for MHDs as a process whereby the personal becomes increasingly interpersonal. The process begins with an awareness of difficulties and an appraisal that help is needed. This develops to young people being able to articulate difficulties to others and sources of help being available. Finally, the young person must be willing to disclose difficulties and seek help.

Evidence is emerging to support Rickwood et al. (2005)'s theory of young people's help-seeking for MHDs. Wright and colleagues (2005) analysed data using a content analysis to explore how awareness and beliefs about psychosis may influence help-seeking from the perspectives of a general population sample of 1027 Australian young people aged 12 to 25

years. Young people's ability to recognise MHDs as clinically defined and to identify the type of help that they thought was appropriate were assessed. Results showed that only a quarter of young people were able to identify psychosis from a vignette. A further study of the same data suggested that young people who were able to identify psychosis accurately were less likely to suggest that the person in the vignette should deal with the problem on their own and more likely to suggest seeking help from the appropriate professional services (Wright, Jorm, Harris, & McGorry, 2007). These studies therefore suggest that recognition of psychosis may encourage help-seeking from professionals. However, caution is warranted as to whether the findings are predictive of young people's actual beliefs and responses towards individuals with psychosis as they present in real world situations. In addition, the quantitative survey technique did not allow the researchers to clarify what young people understood by psychological and psychiatric help.

A study analysing retrospective accounts of 12 young people with psychosis using a general inductive approach identified that adolescents who develop psychosis also had a limited awareness of MHDs prior to developing difficulties, which participants reported may have delayed their help-seeking (Cadario et al., 2011). Furthermore, a number of studies have found that young people often do not initially identify that their experiences may constitute MHDs (Judge, Estroff, Perkins & Penn, 2008; Cadario et al., 2011; Tanskanen et al., 2011). These studies reported that young people generated meaningful accounts of their experience, for example, attributing them to stress or personal experiences, and often did not attribute changes to MHDs before receiving a diagnosis. It appears that in the early stages of psychosis many young people do not consider that their experiences may indicate a MHD for which an intervention may be beneficial (Judge et al., 2008; Tanskanen et al., 2011).

While research has been carried out regarding young people's beliefs about their emerging psychosis, information as to how individuals move past these beliefs about their experiences to access help from services is limited. Young people have indicated that it can take a number of months before they disclose their experiences to anyone in their social network (Boydell, Gladstone & Volpe, 2006). There is some evidence that individuals consider help may be needed when they begin to identify that changes are a problem (Hardy, Dickson, & Morrison, 2009). Awareness of stigma appears to affect help-seeking at this stage. Young people report avoiding professional help and finding it difficult to describe their experiences to lay individuals in a way that would not expose them as "crazy" (Judge et al., 2008). It appears that young people's lack of willingness to seek out others and disclose difficulties, as identified by Rickwood et al. (2005), does delay help-seeking. However, it is unclear which beliefs contribute towards this unwillingness.

It has been recognised that those in a person's social network may perceive a problem when the young person does not perceive it and subsequently either initiate help-seeking themselves, or support the individual experiencing psychosis to access care (Morgan et al., 2005). In response a number of studies have been undertaken exploring help-seeking in families of young people with experiences of psychosis using grounded theory, thematic analysis and phenomenologically based approaches. As with young people themselves, family members report not initially recognising changes in the mood or behaviour of their relative as being indicative of psychosis. Parents described that they first noticed behavioural changes, withdrawal and somatic symptoms such as loss of appetite or sleep disturbances (Cardario et al., 2011) and typically attributed these to developmental changes considered as common features of adolescence, stress, depression, or drug use (Czutcha & McCay, 2001; Bergner et al., 2008; Tanskanen et al., 2011). Families primarily appeared to seek support

when evidence of psychosis became visible through behaviour, for example, when they experienced the young person's behaviour as "alarming" or "risky" (Corcoran et al., 2007; Bergner et al., 2008). Importantly, families also frequently reported stigma such as negative reactions from others to their relatives' increasingly worrying behaviour, and felt reluctant to engage with mental health services because of the negative stereotypes this evoked (Franz et al., 2010). The Network Episode Model (Pescosolido, 1991, 1992) highlights the impact of the beliefs of those within the social network and it would be useful to know whether young people's perceptions of their relatives' beliefs impact on their own beliefs towards their experiences and help-seeking.

1.3 Rationale for the Present Study

Further research is required to understand how young people's beliefs about the nature of their experiences, and beliefs about accessing services may facilitate or hinder help-seeking. Given the considerable role of social networks in help-seeking for this population, it is important to understand how the beliefs of others impact on young people's beliefs about help-seeking. Listening to the beliefs and experiences of young people that have lived experience of accessing EIP services is important in achieving these aims. In addition, the need for research set within a UK context has previously been emphasised (Rothi & Leavey, 2006), with some suggesting this should be explored within varied regions in the UK where people may differ in knowledge and cultural norms (Brunet & Birchwood, 2010).

The present study therefore aimed to explore how beliefs about disclosing experiences of psychosis to others, and accessing professional support, impacted on decisions regarding help-seeking during FEP for young people within a largely rural UK population. Importantly,

it explored young people's beliefs about the beliefs of others in their social environment prior to help-seeking. This study aimed to provide further understanding of help-seeking processes for young people with FEP, in order to promote help-seeking. This is an essential step in ensuring that young people access appropriate, evidence-based services.

1.4 Research Questions

This study addressed the following research questions:

- 1) How do young people's own beliefs regarding the nature of their experiences or services influence initial help-seeking for FEP?
- 2) What are young people's beliefs about others' beliefs about MHDs or help-seeking and how do these social network beliefs influence help-seeking?

2. Methodology

2.1 Design

The design was a qualitative grounded theory study using semi-structured interviewing (Corbin & Strauss, 2008). This approach was considered appropriate to gather detailed accounts of young people's experiences that were not required to fit pre-determined categories. Grounded theory also moves beyond descriptive findings, and allowed for the construction of an explanatory theory of young people's beliefs about help-seeking, capturing complex relationships between beliefs, that were grounded in the beliefs of the young people interviewed.

2.2 Participants

Twelve participants were recruited from a largely rural NHS EIP service. Participant demographic information can be found in Table 1. Inclusion criteria required participants to be: aged 18 to 25; able to participate in English; able to provide informed consent; and to have accessed an Early Intervention Service within the previous three years. The only exclusion criterion was a current diagnosis of alcohol or substance abuse disorder (as people who abuse substances are anticipated to have a different engagement pattern). No participants were excluded on this basis.

Table 1

Participant demographic information

Demographic	
Participants	n= 12
Age	Range= 18-25 Mean= 20.9
Gender	Female= 6 Male= 6
Ethnicity	White British= 12
Employment status	Employed= 5 Attending College=3 Unemployed= 4
Time since first access to EIP team	Range= 1 month-3 years Mean= 1 year 8 months

All participants had recently consented to being included on a research register for the service, indicating that they would be willing to be contacted regarding opportunities to participate in research. Participants were contacted in the order in which they signed up to the research register. Two individuals declined participation citing difficulty with time commitments due to recently undertaking full-time work.

2.3 Ethical Considerations

Ethical approval was given by the local NHS Research Ethics Committee (Appendix 6) and Research and Development approval was granted by the NHS trust (Appendix 7). The study adhered to the British Psychological Society and the Health Professionals Council code of ethics and conduct (British Psychological Society, 2006; Health Professionals Council, 2009).

2.4 Procedure

The care co-ordinators of participants on the research register were contacted to ascertain whether it was appropriate to approach individuals, taking into account their current levels of distress or perceived risk. Subsequently, the researcher contacted potential participants directly and provided information regarding the study (Appendix 3). As suggested by the ethics committee, interviews were scheduled at least 24 hours after the provision of information, and written consent was obtained at the beginning of each interview (Appendix 4). Face-to-face semi-structured interviews were conducted with all participants in a convenient community setting, for example youth centres or clients' homes. Interview questions were guided by the research aims and addressed beliefs about mental health and help-seeking (Appendix 5). The questions were reviewed by a service-user research group

and by the lead project supervisor who was experienced in working with young people with psychosis. The interview guide was also piloted with a focus group of 18 to 25 year olds with a range of MHDs, who felt that the questions were clear and relevant. Those in the pilot group suggested individual interviews would be preferable to a focus group to allow participants to speak more openly. Questions were adapted as interviews progressed in response to emerging findings (Corbin & Strauss, 2008). The interviews lasted approximately 60 minutes and were digitally recorded, transcribed and anonymised for analysis. Interviews took place over a period of two months.

2.5 Data Analysis

Data was analysed using NVivo 9, a software programme designed to facilitate the coding of qualitative data. In line with grounded theory (Charmaz, 2006; Corbin & Strauss, 2008) data were initially coded using line-by-line or incident-by incident coding following each interview. A process of focused coding was then undertaken, in which salient codes were analysed in more detail and used to make further sense of the data. During focused coding analysis was concentrated specifically on data relating to beliefs. This was considered as data in which young people reported an appraisal of a situation including its nature and potential responses, or described this occurring in others as an indication of the social network beliefs. Constant comparison was used to evaluate similarities and differences in the data as interviews progressed (Charmaz, 2006). Codes were then progressively grouped into categories that were explored in subsequent interviews to allow for deeper understanding of the concepts. Analysis of the data continued until no new properties of the categories were found, and it was considered “theoretical sufficiency” had been achieved (Dey, 1999). On completion of the interviews, final categories were integrated into overarching sub-categories that were used to create an explanatory model.

2.6 Quality Assurance Checks

A reflective research diary (Appendix 8) was kept throughout the conceptualisation and implementation stages of the project to increase awareness of assumptions and minimise their influence during data collection and analysis. Quality of the data was enhanced by means of regular review by the lead supervisor, who also conducted an independent analysis of the data in order to cross-check emerging codes. Memos were reviewed in supervision throughout coding in order to ensure transparency regarding the emergence of ideas. Direct quotations are used verbatim to increase the credibility of the theoretical model by grounding it in direct examples from the data.

3. Results

Coding resulted in 87 focused codes. Further analysis resulted in the formation of seven categories and numerous sub-categories (see Table 2). All categories, sub-categories and related codes can be found in Appendix 10. These categories were used to create a model which is illustrated in Figure 1.

3.1 Summary of the Model

The data showed that young people developed multiple beliefs about their experiences and about help-seeking. Three primary categories included beliefs that experiences were normal or abnormal, beliefs about the process of help-seeking, and beliefs about the outcome of help-seeking. These beliefs were considered primary because they directly linked to the development of beliefs about needing help. Four categories of secondary beliefs were considered as providing a context for the development of the primary beliefs about

experiences and help-seeking. Two of the categories of secondary beliefs included perceptions about others beliefs, about whether experiences were normal and about the outcome of help-seeking. Two further secondary categories of beliefs that were also important for how young people understood their beliefs about help-seeking were existing beliefs about MHDs, and beliefs about the impact of experiences on the self.

Young people reported that beliefs could either inhibit or promote disclosure of difficulties and help-seeking. Overall there were more inhibiting beliefs than promoting beliefs. It was found that beliefs that inhibited or promoted help-seeking were qualitatively different, rather than being the opposite of one another.

Social networks were important to young people's beliefs about help-seeking in three ways. Firstly, as illustrated by two of the secondary categories of beliefs, young people reported that their perceptions of other peoples' beliefs influenced their own beliefs about whether their experiences were normal, and about the outcome of seeking help. Secondly, the beliefs young people had about others' negative reactions to disclosures of their experiences were important. Finally, beliefs about the impact young people envisaged help-seeking would have on others, in particular family members, affected decisions about help-seeking.

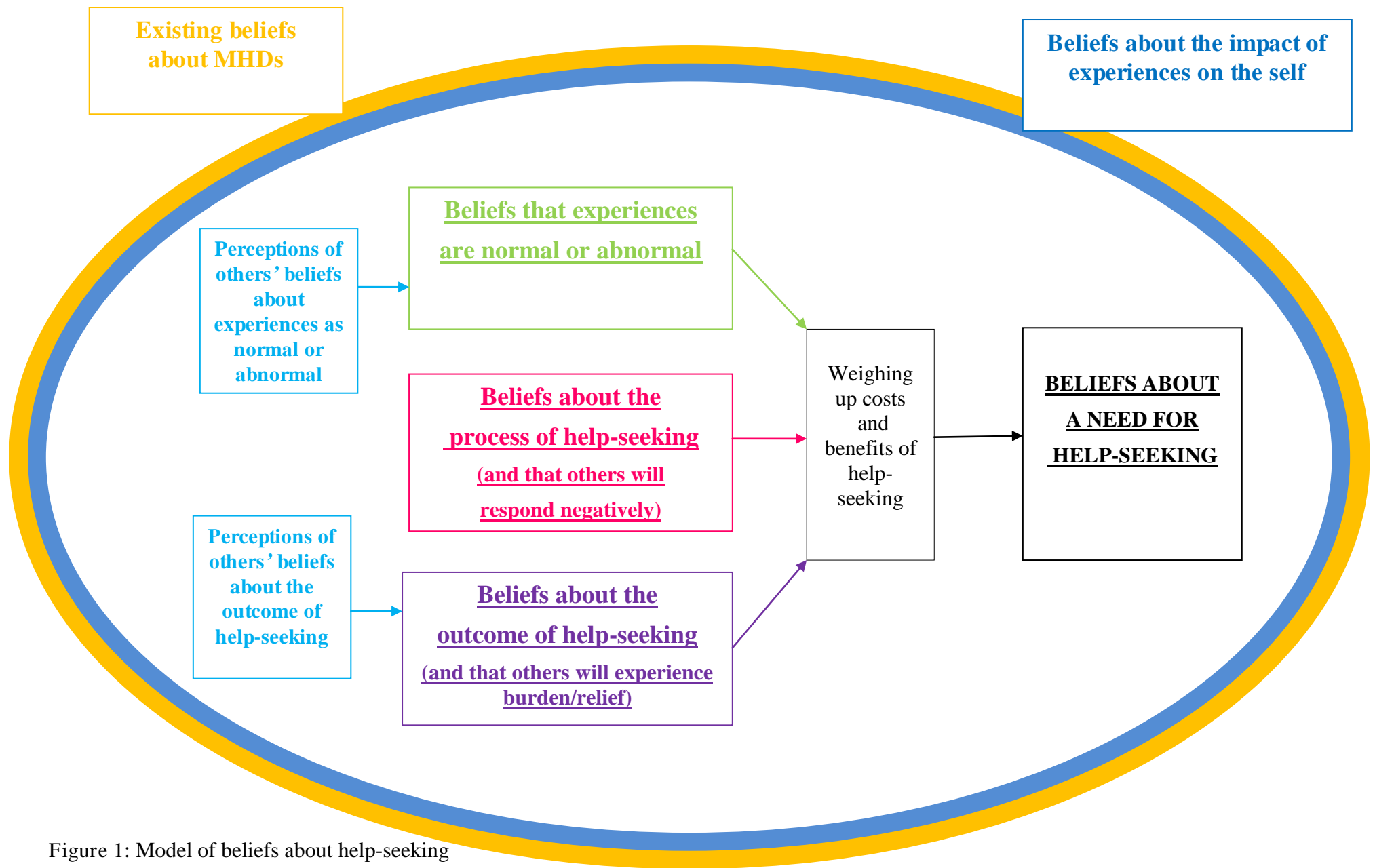


Figure 1: Model of beliefs about help-seeking

Table 2

Categories and sub-categories of young people's beliefs

	Category	Subcategories	
	Primary beliefs	Inhibits help-seeking	Promotes help-seeking
1	Beliefs that experiences are normal or abnormal	Beliefs that experiences are normal Beliefs that services are not necessary	Beliefs that experiences are not normal Beliefs that there is a problem Beliefs that one is unable to cope with experiences
2	Beliefs about the process of help-seeking	Beliefs that it will be difficult to tell someone Beliefs that others will respond negatively	Beliefs that it is safe to disclose experiences
3	Beliefs about the outcome of help-seeking	Beliefs that help-seeking will have negative consequences for oneself Beliefs that through disclosing the young person will become a burden to their family Beliefs that services will not be helpful Beliefs that one is unhelpable	Beliefs that disclosing experiences will relieve current distress of family Beliefs that change is possible Beliefs that services could provide help
	Secondary Beliefs	Inhibits help-seeking	Promotes help-seeking
4	Perceptions of others beliefs about experiences as normal or abnormal	Beliefs that others believe that <i>the young person's behaviour</i> is normal	Beliefs that others believe that <i>the young persons' behaviour</i> is not normal Beliefs that others believe that something has changed for young person Beliefs that others believe that that young person needs professional help
5	Perceptions of others beliefs about the outcome of help-seeking	Beliefs that others believe that service use will have negative outcomes	Beliefs that others believe that services will be helpful

	Secondary Beliefs	Inhibits help-seeking	Promotes help-seeking
6	Existing beliefs about MHDs	Beliefs that MHDs are socially undesirable Beliefs that MHDs do not affect young people	Beliefs that MHDs are understandable
7	Beliefs about the impact of experiences on the self	Beliefs about isolation Beliefs that experiences mean something bad about oneself	

A description of each of the categories, with exemplifying codes, is presented below.

3.1.1 Beliefs that experiences are normal or abnormal.

Understanding experiences as normal or abnormal was a dynamic process as young people described beliefs about their experiences as fluctuating, rather than as moving from normal to abnormal. Whether beliefs were considered normal or not had an inhibiting or promoting effect on beliefs about a need for help-seeking. This appeared dependent on whether more ‘normal’ attributions provided a satisfactory explanation of experiences.

3.1.1.1 Inhibiting factors

Beliefs that experiences are normal

Young people frequently gave descriptions of how they initially normalised their behaviour by characterising it as an understandable response to factors such as being a teenager, taking drugs, or difficult life events. In some cases young people reported not noticing that anything was unusual or different:

“...when I first got ill I didn’t think there was anything wrong so I didn’t think there was anything to tell.” (Participant 3)

Beliefs services are not necessary

A minority of young people reported that their experiences had not caused them any difficulty prior to accessing services. These young people had not believed that anything was wrong, and therefore had not believed that services were necessary. This was often a situation in which others were involved in supporting the young person to seek help:

“I told him he was the crazy one and he said er, I don’t think so (name of participant), you’re losing the plot, or something like, and I was like, ‘Dad I think you’re bonkers,

let's get you sectioned'. And he was like 'No, no, you need to see a doctor', and I was like 'No, you need to see a doctor.' (Participant 6)

3.1.1.2 Promoting factors

Beliefs that experiences are not normal

Young people expressed beliefs that their experiences signified that something was wrong. Some participants described perceiving changes in mood and behaviour that were incongruent with their usual personalities, causing them to feel uncomfortable:

"Some of the behaviours that were quite scary, very out of character for me, I felt very out of control." (Participant 7)

Others talked about hallucinations or paranoia becoming extreme and fear inducing, and knowing that these experiences could not be rationalised as something normal:

"I was hearing voices at this stage that weren't my own, and it became normal to me but at the same time I knew that it wasn't ok." (Participant 5)

Many described having thoughts about ending their own life as signifying that something was wrong:

"I just got to a point where I was like, this isn't right, these thoughts aren't making me feel good, they're not making me feel ok, they're making me feel like I want to kill myself, so I just thought that can't be right." (Participant 5)

Beliefs that there is a problem

Young people described that a realisation that there was a problem seemed to develop when experiences became overwhelming. With this there was also a recognition that they needed to change their experiences:

“I decided to go back to college and that’s when I realised I had a problem. Cos I found it hard even being in a room with other people.” (Participant 10)

Beliefs that one is unable to cope with experiences

Participants predominantly explained they knew others’ support was needed when they were no longer able to cope with their experiences:

“The voices were really, really coming on strong, so I left work and came home early...I left it for ages and in the end it got so bad I phoned the mental health line and described what I was feeling.” (Participant 11)

3.1.2 Perceptions of others beliefs about experiences as normal or abnormal.

Young people reported that beliefs about whether others’ has noticed changes in them, and whether others viewed these changes as normal or not influenced their own beliefs about their experiences. Participants’ beliefs about whether help was needed appeared to be influenced by their perceptions of whether others thought professional help was warranted.

3.1.2.1 Inhibiting factors

Beliefs that others believe that their behaviour is normal

Young people's beliefs that their experiences were normal were influenced by other people voicing similar perceptions, for example, parents telling them their behaviour was part of adolescent development, a reaction to life events or attention seeking:

"Part of the reason I didn't seek help earlier was my mum blamed me just being a teenager, and my dad, just said I was going through teenage stuff, and so I was just like oh ok." (Participant 5)

Others reported parents telling them they would move past their experiences in time:

"My mum thought I'd be alright and give it a while and you'll be fine." (Participant 2)

3.1.2.2 Promoting factors

Beliefs that others believe that something has changed for them

There was often a sense from participants that others, including both friends and family, had noticed a change. Changes included others commenting that the individual seemed more withdrawn, or had excessive energy. At times this was before the young person themselves had noticed anything.

"I think if it weren't for my mum and dad telling me, 'oh you're acting differently' and stuff like that then I probably wouldn't have noticed at all." (Participant 2)

Beliefs that others believe that their behaviour is not normal

Young people reported others experiencing their behaviours as concerning:

“I think they were just scared and worried and not quite knowing what was going on.” (Participant 1)

Sometimes, others beliefs that their behaviour was unusual influenced their beliefs, but participants reported that sometimes these beliefs were unfounded:

“I thought everyone was completely wrong, like I didn’t believe that I was ill at all, I couldn’t see it.” (Participant 3)

Beliefs that others believe that professional help is needed

Participants spoke about beliefs that their family members thought that they were in need of support. One way this arose was when a family member felt they could no longer do enough on their own to help the young person without professional help:

“I think he wanted to do more than he could have done, like he just, he knew he *couldn’t help me alone.*” (Participant 8)

There often seemed to be a strong emphasis from others that accessing professional support was a good option, and this had influenced participants:

“I: So what was different about that time?

P: My mum making the decision to call the doctor, and putting it out there, and I agreed.” (Participant 10)

3.1.3 Beliefs about the process of help-seeking.

Beliefs in this category also both promoted and inhibited beliefs that help was needed. This included beliefs about what the process of disclosing to someone might be like, the conditions that impact on this, such as timing and environment, and how others might respond to initial disclosures. Beliefs about the process of engaging in professional help were also important.

3.1.3.1 Inhibiting factors

Beliefs that it will be difficult to tell someone

Some participants reported believing that it would be difficult to explain their experiences to others when there appeared to be no identifiable cause, such as an unpleasant life event, or when they were confused about the nature of their difficulties:

“The only thing I could think of was thinking about the feeling that I’m getting, but it was a lot easier for people to say I feel depressed because I’ve split up with my partner or because this happened, but there was no real reasons apart from this feeling that I’ve had that was enabling me not to do things.” (Participant 10)

Beliefs that others will respond negatively

Other important beliefs reported by participants about disclosing to others were uncertainty and anticipation of negative responses:

“No, I didn’t know what she’d think or what she’d do so I just thought I’d keep it a secret.” (Participant 11).

Beliefs about not being taken seriously seemed particularly important to young people who were attending school, especially if they had witnessed peers being judged negatively after disclosing similar difficulties:

“Cos basically everyone was saying behind her back, *‘oh she’s an attention seeker’*, I thought if people found out about mine then they would say the same thing. Cos that’s what it’s kind of seen as *in school*.” (Participant 11).

3.1.3.2 Promoting factors

Beliefs that it is safe to disclose experiences

Many young people reported that it was easier to disclose their experiences if ‘permission’ was given for this in the form of others directly asking about experiences of psychosis, or by others sharing that they had also had MHDs:

“*It wasn’t really until I got help that I told anyone about it cos the questions got asked, like, ‘Have you seen anything unusual?’ and I talked to people about it.*”
(Participant 3)

Perceptions of others’ ability to understand their experiences seemed important to participants, and a belief that it would be more useful to talk to someone that had experienced MHDs was raised. Beliefs that help was needed formed more readily if young people believed there was someone they could rely on for support. Characteristics of the person they were disclosing to were important, with young people needing to believe that the person could be trusted, would listen and would not judge them:

“I knew that she wouldn’t be the type that you’d tell her and then she’d be gossiping about it behind my back to all my other friends.” (Participant 4)

3.1.4 Beliefs about the outcome of help-seeking

Beliefs about the outcome of help-seeking also affected young people’s beliefs about a need for help-seeking. Inhibiting beliefs were generally more prominent than promoting beliefs. Beliefs about whether help-seeking would have a positive or negative impact on family members were considered important. These beliefs are explored further below.

3.1.4.1 Inhibiting factors

Beliefs that help-seeking will have negative consequences for oneself

Many young people feared that help-seeking would have negative consequences, including immediate consequences such as being locked up in a psychiatric unit. Young people also mentioned awareness of potential losses including important relationships with friends and family, and opportunities in future education and employment:

“...so I didn’t want to lose those friendships because it felt good, like every weekend we’d have a laugh just playing football and if we won we were like, yeah, yeah, and if we lost it was like it doesn’t really matter, we’ll win next week... I didn’t want that to go sort of thing.” (Participant 2)

“...all I kept thinking was if I tell someone they’ll section me and I’ll never be able to work with kids, cos I didn’t know anything about it that’s what I thought, so that’s the main reason why I didn’t tell anyone.” (Participant 8)

Beliefs that through disclosing the young person will become a burden to their family

A number of the participants indicated that engaging in help-seeking might be a burden to their families. For some this included adding pressure to environments in which parents were already facing substantial financial or health problems. Others had family members with existing MHDs, and felt that revealing their own difficulties would add more stress to the family system:

“And it worried everyone, and I thought it’s the last thing that everyone needs to say actually we’ve got two depressed people in the family.” (Participant, 12)

For some young people it appeared that asking for help from others was not typically part of their family coping strategies, and therefore any disclosure of difficulties that may require support was considered a burden:

“I think that everyone’s better off without knowing everything I go through so I just leave it.” (Participant 9).

Beliefs that services will not be helpful

For some, beliefs that services would not be helpful developed from previous experiences of disclosing difficulties and not having them acknowledged or not having appropriate help provided:

“Because of like the (place name) mental health team wasn’t very good, I just thought that the rest would be like that.” (Participant 1)

Other young people expressed uncertainty about what would happen to them, with some believing that treatment offered by services would be negative:

“I was scared of being unnecessarily treated. Obviously you hear about the more *extreme ends, or the more extreme parts of mental health, whether it’s electric shock therapy.*” (Participant 7)

Beliefs that one is unhelpable

Young people’s beliefs that they could not be helped had a further negative influence on decisions about help-seeking. These beliefs were often expressed by participants who later considered or attempted a suicide attempt:

“I still felt like I was wasting these people’s time, like I was beyond help, that I was, you know, better off topping myself.” (Participant 5)

3.1.4.2 Promoting factors

Beliefs that change is possible

The belief that change was possible was important in prompting help-seeking. Young people reported reaching a stage where they believed their difficulties were something that could be overcome:

“I was so determined not to let it beat me, to carry on.” (Participant 5)

Beliefs that services could provide help

Associated with the belief that change was possible was the belief that accessing professional services might be helpful, through professionals understanding participants' experiences and either providing answers, or supporting individuals to move past their difficult experiences. Young people were aware that services might provide them with both treatment in the form of medication, and therapy:

"I suppose I was hoping for anti depressants and I was hoping for some kind of er, therapy." (Participant 7)

This belief was positively influenced by seeing family members or peers experiencing positive outcomes from using mental health services:

"...you've seen her being quite unwell and then the doctor comes round or the nurses and you know giving her, her medication....and you see her get better."

(Participant 10)

Beliefs that disclosing experiences will relieve current distress of family

In contrast to beliefs that seeking help would burden their families, some young people expressed beliefs that it would relieve stress caused by their families' awareness of their difficulties. Within these situations young people reported that the belief that that they were causing their families worry or pain motivated them to disclose difficulties:

"I saw how it impacted my family and that they really nearly lost me and they was stepping on egg shells all the time trying not to upset me, and I just thought it was really unfair on them, so I finally got up the courage." (Participant 12)

3.1.5 Perceptions of others beliefs about the outcome of help-seeking.

Some young people perceived that others had beliefs about whether services would be helpful or not, and reported that this was influential on their own beliefs about using services.

3.1.5.1 Inhibiting factors

Young people's beliefs that others believe that using services will have negative outcomes

Young people reported parents' beliefs that time spent in a psychiatric ward would not be helpful, and the young person might be labelled:

"I remember Dad drove me to the hospital and he was in tears at the, at the wheel cos they were very, very scared of me being labelled or I guess of me being crazy."

(Participant 7)

In addition, knowledge of others beliefs that services were unhelpful due to others' experiences of using services also created beliefs that help-seeking would not be useful:

"Obviously the service she got were absolutely useless, she went to see her doctor he *didn't want to know, she went to the hospital they didn't want to know, they said that* she was making it up and I thought like people might not be able to believe me. Like *the doctors didn't* believe her. So yeah she had a bad experience and that definitely put me off." (Participant 12)

3.1.5.2 Promoting factors

Beliefs that others believe that services will be helpful

Other young people reported that family and friends actively suggested that they access professional help for their difficulties, and participants cited this as a factor that positively influenced whether they sought help:

“Mum just sat me down and was like what’s the matter?...Let’s just go and see somebody just in case like there’s a problem, and we can sort it out.” (Participant 8)

3.1.6 Existing beliefs about MHDs.

The participants’ existing beliefs about MHDs appeared important in the development of many of the beliefs about help-seeking already discussed.

3.1.5.1 Inhibiting factors

Beliefs that MHDs are socially undesirable

The belief that MHDs are a weakness or something to be feared made young people less likely to want to identify their experiences in this way:

“You know going through some mental health issues, there’s still so much stigma about it like it’s a weakness.” (Participant 5)

Beliefs that MHDs were undesirable were linked to beliefs about the process of help-seeking. For example, young people who believed MHDs were a weakness or should be feared also believed others would respond negatively to disclosures, and placed more

emphasis on needing a safe environment in which to disclose. Existing beliefs about MHDs were also important in relation to beliefs about the outcome of help-seeking, for example, that people with MHDs should be avoided or locked away, and increased beliefs that help-seeking would have negative outcomes for oneself. Similarly, these beliefs increased thoughts that individuals would be a burden to their family:

“There was a sense of just wanting to keep things normal at home and I didn’t want them to treat me any differently or anything like that. Or you know be ashamed of me, or feel I was a burden or anything like that.” (Participant 7)

Beliefs that MHDs do not affect young people

Some participants believed that MHDs do not affect young people:

“Well cos you think when you’re young, you don’t think that you’re having a mental health problems, like when you’re having a mid-life crisis or something, you don’t think that it can happen to someone who’s 18.” (Participant, 10)

Holding this belief, whilst acknowledging that one’s experiences may constitute a MHD, appeared related to the formation of beliefs about ‘not being normal’.

3.1.5.2 Promoting factors

Beliefs that MHDs are understandable

Some participants had family members with MHDs and these young people often believed that such difficulties were understandable. If young people had experienced family

members recovering after experiencing difficulties, they were likely to believe that change was possible:

“I: So, what were your perceptions of mental health difficulties before seeing services?

P: That, its quite understandable really, cos of my Nan and that...you can get over it.”

(Participant 10)

Participants that believed that MHDs were understandable reported being more confident about disclosing their experiences to others.

3.1.6 Beliefs about the impact of experiences on the self.

Experiences of psychosis had a significant impact on young people’s perceptions of themselves and this appeared to have an inhibiting affect on beliefs about help-seeking.

Beliefs about isolation

The majority of participants described believing they were the only person who had unusual experiences:

“I was on me own, and I was the only person in the world with this problem.”

(Participant 2)

Beliefs about isolation were increased for participants that did not consider that MHDs were experienced by younger people. The belief that they were alone in their experiences increased young people’s perceptions that others would respond negatively to disclosures. Beliefs about isolation also inhibited help-seeking as participants reported believing that there was no one to talk to and the other people were not interested in them.

Beliefs that experiences mean something bad about oneself

Young people described believing they were different from others, and described believing prior to help-seeking that they were a failure, damaged, or weak:

“I kept *thinking oh I’ve given up, I’ve failed sort of thing.*” (Participant 2)

“I felt kind of weird or damaged.” (Participant 7)

For those participants that believed MHDs were undesirable and subsequently began to identify as having an emerging MHD, negative self-beliefs became more entrenched. Beliefs of being abnormal gained further prominence, creating ambivalence between believing help was needed and not wanting to be identified as having a MHD:

“I kind of thought everyone with mental health issues were lunatics which obviously *didn’t help my perception of myself.*” (Participant 5)

Beliefs about the process of help-seeking that inhibited help-seeking decisions, such as expecting others to respond negatively to disclosures, occurred alongside participants believing that their experiences meant something bad about them. In addition, participants that reported negative self-beliefs appeared to believe that seeking support would have negative outcomes.

4. Discussion

This study proposes a preliminary model to explain how beliefs about help-seeking and the perceived beliefs of others can contribute to making a decision that help is needed for FEP by young people in the UK. This model is unique in considering how young people's beliefs about what other people think affect their own beliefs about a need for help-seeking both in terms of understanding whether experiences were normal or not, and in considering the likely outcome of help-seeking. Young people's beliefs regarding whether their experiences were normal or abnormal, and beliefs about the process and outcome of help-seeking contributed to formation of beliefs about whether help was needed. It was also found that young people's beliefs about MHDs prior to help-seeking, and the impact that experiences of psychosis had on their self-perception, were important in developing beliefs about a need for support.

4.1 Links to Previous Research and Theory

4.1.1 Awareness of difficulties

This study supports and elaborates previous understandings of young people's help-seeking for psychosis. Rickwood and colleagues (2005) identified awareness of difficulties as an essential precursor to appraisals that help is needed. The current study suggests that, consistent with previous studies (Judge et al., 2008; Cadario et al., 2011), young people are often aware of difficulties but reported that they did not always identify changes as MHDs, and often conceptualised them initially as a normal part of life. Other beliefs demonstrating awareness were important in decisions to seek help, for example, beliefs about whether their experiences signified a problem and whether they believed they could cope with their experiences. Young people's recognition of a problem was characterised by experiences

becoming overwhelming, in terms of the distress or impact on functioning. For those young people who had not believed there was a problem, the actions of others were important in recognising that something had changed and supporting them to access professional help as has previously been found (Cadario et al., 2011). Therefore this study supports that an awareness of difficulties is important for help-seeking in psychosis.

4.1.2 Self-stigma

A great deal of research has indicated that stigma may be a significant barrier to accessing mental health services (Thornicroft, 2006; Judge et al., 2008, Tanskanen et al., 2011), and young people in this study similarly reported beliefs of other people reacting negatively to disclosures as being an inhibitory factor. Young people also reported that before they had experienced psychosis they had seen MHDs as something shameful and stigmatised. Internalisation of societal stigma by people with MHDs is known as self-stigma (Corrigan & Watson, 2002). Previous studies of self-stigma have been carried out with people who are already using mental health services (Knight, Wykes, & Hayward, 2001). This study highlights the potential impact of self-stigma even prior to help-seeking for young people with FEP, demonstrated by young people's pre-existing beliefs about MHDs and beliefs about the impact of experiences on the self.

Participants reported that having unusual experiences resulted in beliefs that they were odd, weak or damaged. This has particular relevance in view of the fact that the majority of young people experienced these changes during adolescence, typically a time of transition and change. Erikson (1994) describes this as a period of identity formation, forging between 'who one has become' and 'who society wants one to be'. This has significant implications

for the identity of young people who ‘have become’ a person with psychosis, in a society where stigma towards MHDs is prominent. For young people within this study, beliefs about whether they were normal or not were often a marker of whether to seek help. Yet a belief of being abnormal also created self-stigma which inhibited accessing support. Psychological approaches which consider experiences of psychosis on a continuum with normal experience (Bentall, 2011), and instead focus on distress as an indicator for help, may reduce self-stigma beliefs which inhibit young people seeking help.

4.1.3 Willingness to seek help

Rickwood et al. (2005) suggest the final stage of young people’s help-seeking is being willing to seek out help and disclose their “inner worlds”. Experiencing self-stigma prior to help-seeking leaves young people in a particularly vulnerable position of making a decision of whether to disclose experiences which both society and they themselves view as unacceptable. The current findings suggest that beliefs about the process of help-seeking may be important in willingness to seek help, especially when considered alongside perceived stigma and self-stigma. Young people described being more likely to disclose to an individual that they believed could be trusted and would understand their experiences, rather than judge them. Participants emphasised the importance of ‘permission giving’ from others in the form of asking whether young people were experiencing difficulties, or sharing their own experiences of MHDs. Beliefs about whether they would be taken seriously, would be viewed as “attention seeking” or would be gossiped about by peers were also important.

4.1.4 Social networks

The Network Episode Model (Pescosolido, 1991, 1992) considers professional help-seeking as bound within a socially interactive context, and this study found that the beliefs of others served roles of both inhibiting and promoting young people's beliefs about help-seeking, specifically about whether difficulties were normal or abnormal, and about the outcome of help-seeking. Social networks were also important in influencing young people's perspectives about help-seeking in the consideration young people gave to other's reactions to disclosures and the impact (i.e. burden or relief) young people envisaged help-seeking would have on others, in particular family members. Previously impact of help-seeking on others has been conceptualised as an inhibiting factor, with young people reporting they do not want to cause their families anxiety by sharing experiences (Boydell et al., 2006). Importantly, this study also found that young people were more likely to disclose difficulties if they perceived it would relieve pain or worry within the family about their observable changes.

4.2 Clinical Implications

This study has important consequences for educational interventions and for clinicians engaging with young people with FEP. Young people reported that they frequently struggle with beliefs about whether their experiences are normal or not. It is important to educate young people to recognise that they may benefit from support, as a result of the distress and impact on functioning their experiences cause, and not because their experiences are abnormal. The challenge for health care providers is to enable young people to be able to access this support in a way in which they do not believe they are "weak, odd or damaged", and in which individuals in their social networks do not experience as threatening.

Participants described social networking sites as a useful place where this information could be accessed. Evidence has already been found in some areas that young people are comfortable seeking help online (Burns et al., 2009). In working therapeutically with young people with FEP clinicians must be prepared to dispel pre-existing beliefs that young people have about MHDs and beliefs that experiences mean something negative about themselves. Continuing to engage an individual in accessing support may rely on promoting beliefs in the young person that change in levels of distress is possible.

4.3 Limitations

While it is not the aim of qualitative research to generalise across populations, it is important to consider that the sample of participants in this study were predominantly white-British and middle-class. Such factors are important as some studies report that in the UK individuals from African-Caribbean backgrounds are less likely to self-initiate help-seeking, and more likely to access mental health services through the criminal justice service than are those that of white-British origin (e.g. Morgan et al., 2005). In addition, participants within the current study self-selected as being interested in participating in research, which could suggest good general engagement with services, and therefore bias their reports of help-seeking. This sample was comprised of young people that have accessed services, and it would also be informative to capture the views of those who have not. Due to limitations in the information available prior to recruitment of participants, theoretical sampling only involved adapting the direction of the interview questions, rather than the selection of specified individuals. For example, it would have been informative to interview more young people that had family members who had experienced MHDs to further explore the impact this has on their reported pre-existing beliefs about MHDs and beliefs about outcomes of help-seeking. Finally, it is inevitable that recall may not be fully accurate using retrospective

accounts, however, participants were encouraged during interviews to try to describe what their beliefs had been prior to seeking help, and they appeared to be able to do this.

4.4 Future Research

This study suggests that a number of beliefs contribute to decisions about help-seeking. It appeared young people placed different values on beliefs, for example, a key belief that the young person needed help may have overpowered other beliefs inhibiting help-seeking. However, it was not possible to explore this using the qualitative approach taken. Further research could help clarify whether some beliefs are more central to help-seeking than others by forming a measure of help-seeking for FEP, and investigating strength of beliefs quantitatively, and their impact on help-seeking. This would provide further information as to most affective beliefs to target in interventions to promote help-seeking. As highlighted by the limitations of this study, it would also be important to validate such a measure across different populations of young people experiencing FEP.

4.5 Conclusion

This study identified young people's beliefs about experiences being normal or abnormal and beliefs about the process and outcome of help-seeking as inhibiting or promoting help-seeking for FEP. The beliefs of others in the young person's social network were important in this process. Beliefs about whether experiences were normal, pre-existing conceptualisation of MHDs, and beliefs about the impact of experiences on a young person, were suggestive of the development of self-stigma prior to help-seeking. The findings suggest that education campaigns supporting an understanding of when changes become problematic are also important, with a focus on levels of distress and function not abnormality. Further

research is needed to determine if some beliefs are more important to decisions about help-seeking, and to extend these findings to wider populations of young people with FEP.

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MAJOR RESEARCH PROJECT

SECTION C: CRITICAL APPRAISAL

Word Count: 1991 (plus 21 additional words)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

OCTOBER 2012

DEPARTMENT OF APPLIED PSYCHOLOGY
CANTERBURY CHRIST CHURCH UNIVERSITY

1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

Prior to starting clinical training I worked as a research assistant on a randomised control trial, therefore I had prior experience of participant recruitment and quantitative methodology. The process of designing, implementing, and analysing a qualitative study has been a very different experience of research, but one in which I have developed a wealth of experience and skills. Previously, I viewed qualitative research as predominantly being used as a pre-cursor to, or in conjunction with, quantitative work. Through undertaking this project I have come to place a high value on qualitative research in its own right and appreciate the importance of capturing individuals' detailed experiences without using predetermined categories. Important to this was reading thoroughly to understand the different qualitative approaches, and arriving at the decision that grounded theory would be the most appropriate for analysing the data I planned to collect. Through undertaking this study, and considering the quality assurance measures that needed to be taken, I have developed a greater confidence in evaluating other qualitative research, for example by drawing on quality assurance methods such as those proposed by Yardley (2000).

At first I was incredibly cautious with interpreting the data, as it felt very subjective. I was aware of other literature on factors that may predict help-seeking, and despite 'bracketing' my ideas early on, I strove hard to prevent my pre-conceptions from influencing my findings. However, I began to appreciate that it is impossible to be free of pre-conceptions when interpreting data (Thomas & James, 2006). Reflecting on my clinical work had become natural, but I was not familiar with applying reflective skills in the process of

research. However, though using memos and supervision to reflect on the development of my ideas, I gained confidence in coding and comparing different data sets. This was aided significantly by learning to use the NVivo software which I feel was helpful in improving efficiency and therefore conserving time. I would like to experiment further with using this programme in the future, and think it would be helpful for using with small scale service evaluations. I would be interested to develop my skills in using other qualitative methodologies such as interpretative phenomenological analysis and narrative approaches.

Submitting an NHS ethics proposal was a new experience, and the amount of detail required in completing the form was important in allowing me to develop my ideas about the project. From previous work I considered the main ethical issues to be ensuring that participants were not put under undue distress, that they could give full informed consent, and that they were aware that they were free to withdraw their participation at any time. This project taught me the importance of clarity of the research questions and design as being equally as important, in producing research that is of sufficient quality to show findings that may benefit participant care. Writing and submitting an application, and having to amend it following the panels' feedback, is an important experiences for carrying out further research within an NHS setting.

Using semi-structured interviews for research purposes, which are proposed as appropriate for grounded theory (Starks & Trinidad, 2007), was also another skill I learnt during this project. This included developing an interview schedule that addressed relevant topics but was not too prescriptive. Coordinating and gaining feedback from the focus group was key to this process. The pilot group also suggested that I should use individual interviews rather than focus groups as I had originally planned. I have positive experiences of running

groups in the past and thought focus groups would create an environment in which gaining a shared understanding of others' experiences may encourage people to discuss their own. However, the focus group felt interviews would allow participants to be more open. This taught me the importance of consulting with service users over methodology and I am enthusiastic about finding more ways to involve service users in future research I carry out.

I was impressed by the fact that many participants were willing to share incredibly distressing experiences. I had not anticipated how different it would feel listening to individuals' experiences in a research context as opposed to in therapy. It felt difficult at times not to take a therapeutic stance, and so I had to ensure I did not influence the way participants reconstructed their experiences in the interview. It also took time to develop the skill of focusing on the details of participants' accounts that were most relevant to the research questions and, when necessary, re-directing the interview flow. This became easier with experience and as pertinent codes to explore became evident through analysis of the initial data.

2. If you were able to do this project again, what would you do differently and why?

In my initial literature searches I found many studies interviewing families of those who had experienced psychosis, and fewer with young people themselves. Therefore I was enthusiastic to portray the individuals' experiences of help-seeking for psychosis. However, on reflection, it may have been helpful to interview family members as well, which would have been an interesting way to triangulate the data. Two recently published studies, though posing different research questions to the current study, have taken the views of both young

people with psychosis and their families (Cardario et al., 2011; Tanskanen et al., 2011). Furthermore, I had originally intended to contact participants to validate categories with them. However, due to time restraints posed by delays in obtaining NHS ethics approval, I began recruitment later than planned, leaving no time to send my data to participants to be validated following my analysis. This would have added credibility to my findings (Williams & Morrow, 2009) and I would endeavour to pursue this if I ran a similar study in the future.

Although qualitative research does not necessarily aim to be representative, I am aware that the participants in my study were white-British and middle class (as was I as the researcher). This does not minimise the findings of the study, which are consistent with previous studies with different populations, and are important in informing further understanding of help-seeking for first-episode psychosis. However, considering the literature emphasising the importance of culture on help-seeking beliefs (e.g. Pescosolido, 1991, 1992) it is important to consider the meanings this may have for the findings in terms of applicability to other settings. This could include varied perceptions about social network beliefs in different cultures, or different beliefs about services. In addition, coming from a similar ethnic and socio-economic background as the majority of my participants may have heightened the assumptions I made in interpreting the meaning of their accounts. Therefore, if repeating this study I would consider recruiting from a more diverse sample, and would reflect further on assumptions that may be present due to my own ethnicity and class when interpreting the data.

This project was limited in the ability to use “theoretical sampling” as is preferable in grounded theory (Corbin & Strauss, 2008). For example, it would have been useful to further explore the beliefs of young people that have had family members with mental health

difficulties. The four participants that did have these experiences appeared to have more varied beliefs about mental health difficulties, which appeared to impact on beliefs about help-seeking as described in the model. Although attempted, it was difficult to specify for this during recruitment due to confidentiality, and this information could only be accessed after participants had agreed to participate in the project. It is recognised that true theoretical saturation is difficult to achieve (Corbin & Strauss, 2008), and the concept of “theoretical sufficiency” (Dey, 1999) may more accurately represent how researchers decide that their categories are well developed. However, if I repeated the project I would think about alternative ways to access certain participants, such as applying for Research and Development approval for more than one Trust so as to widen the participant pool.

3. Clinically, as a consequence of doing this study, would you do anything differently and why?

The findings from this study highlight the uncertainty and difficult decisions that individuals face in disclosing difficulties to others and mental health services. Clinically, I would pay further attention at a first assessment to the journeys people have taken to access services, and address beliefs they may have about services in a hope that this will increase engagement. I also think it would be important to ask young people about what they think other important people in their life believe about them seeking help, as this research shows these beliefs may support or hinder help-seeking. Also pertinent are beliefs about the process of help-seeking. These include beliefs about the difficulty articulating unusual experiences, and that ‘permission’ that may be needed to disclose difficulties, in terms of a professional

asking about them. In future, if individuals do not bring up any unusual experiences I will feel more confident to ask about them.

This research highlights the difficulties people have had in deciding whether help is needed for their experiences. It is important to consider how to widen service provision to those who do not access needed support. As a clinical psychologist I feel I would be well placed to become involved in education initiatives and strategies to promote young people accessing services earlier. Early intervention for a range of difficulties is well evidence based but increasing young people's awareness of these services and how they may be helpful is needed. If taking a clinical psychologist role in a CAMHS or early intervention team the findings of this project would give me confidence to engage in preventative work by liaising and consulting to schools, primary care, and community organisations.

4. If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

This study found a number of beliefs of young people which may inhibit or promote help-seeking. It would be interesting to explore if the beliefs identified in this study could be used to predict help-seeking behaviour in young people with first episode psychosis. This could involve using the different beliefs as items on a quantitative measure. Each item could be accompanied with a Likert scale to indicate the extent to which young people believed it was relevant to them. Acceptability, reliability and validity could be tested with young people that had recently accessed services, as used in this study. As highlighted by the limitations of this

study, it would also be important to validate such a measure across different populations of young people experiencing FEP.

When undertaking the interviews it appeared that some beliefs seemed more powerful than others in relation to seeking help. This was demonstrated either by the frequency in which they were talked about, or the emphasis young people gave to them. It was not the aim of this study to quantify the importance given to different beliefs, and would not have been possible given the qualitative methodology. Development of a measure of beliefs as suggested could be evolved to test which beliefs are rated as more important than others in inhibiting or promoting help-seeking, and which occur most frequently. Once identified, these beliefs could be used to predict the likelihood of seeking professional support in populations identified as at risk for developing psychosis.

I am aware that this study involved interviewing people who have accessed early intervention services for psychosis. A number of people do not access services for experiences that may be considered as psychosis (Brunet & Birchwood, 2010). I would be interested to carry out a further qualitative study with the aim of identifying whether similar beliefs operate in individuals that do not access services. Possibilities are that these individuals have stronger beliefs that inhibit help-seeking such as believing their experiences are normal, or that other beliefs are present. Once identified, these beliefs could be incorporated into a measure such as that discussed above.

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Appendix 1: Search strategy

The following databases were searched up until week 2 June 2012: Medline (1946-present), PsychInfo (1806-present), CINAHL, Cochrane (2005-present), and Ovid Full Text. The following search terms were used, where * indicates truncation:

‘first-episode’ OR ‘first episode’ OR ‘prodrome’ OR ‘early’ OR ‘emerg*’

AND

‘help-seek*’ OR help seek*’ OR ‘care’ OR ‘treatment’ OR ‘service’

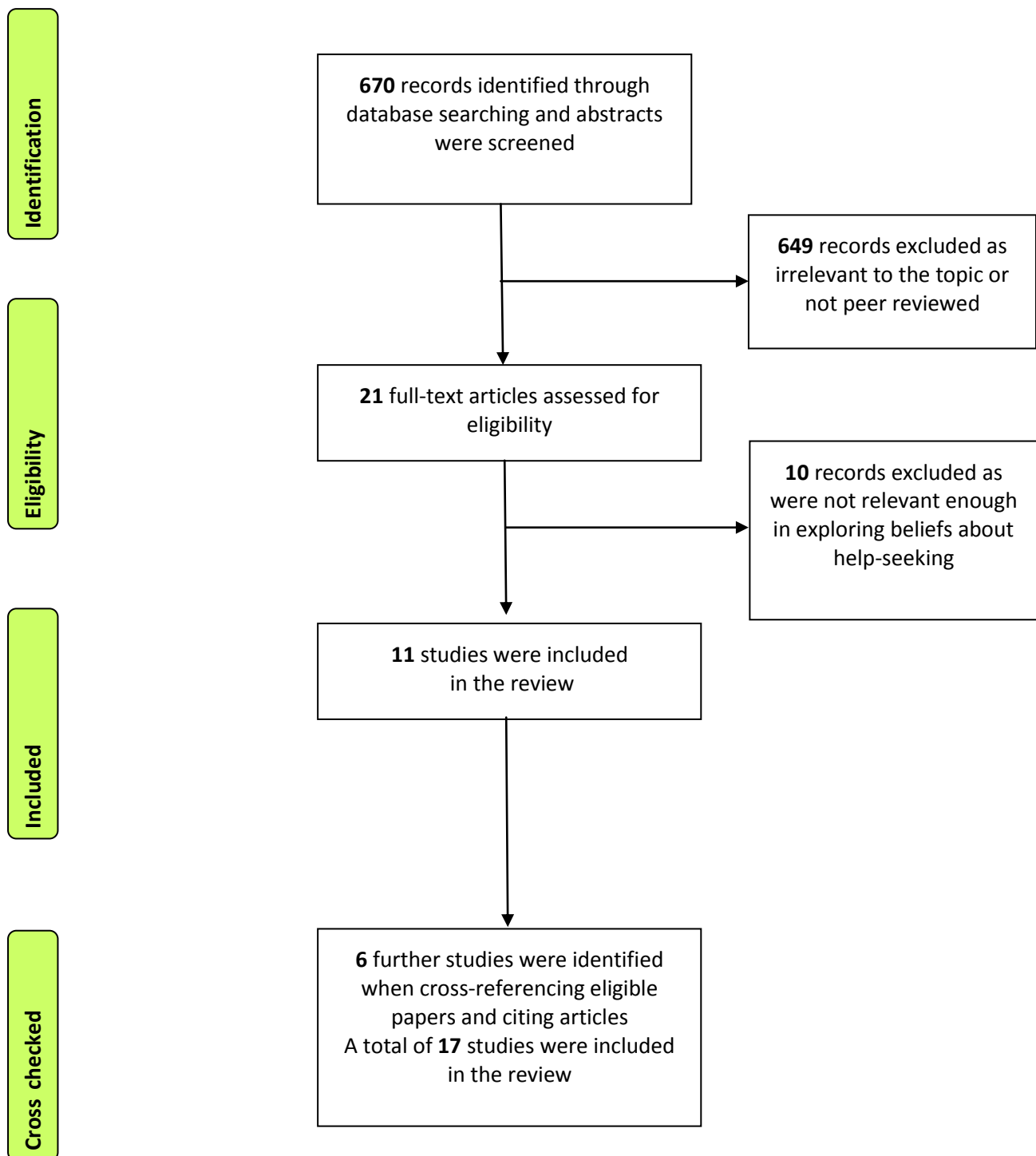
AND

‘Psycho*’ OR ‘schizophr*’

Search terms were kept purposefully wide (e.g. terms about ‘beliefs’ were not included) in an attempt to ensure all relevant studies were retained.

Inclusion criteria were:

- Peer reviewed articles
- Written in English
- Included data which reported findings of beliefs about psychosis or help-seeking from perspective of young person (aged 14-35) or family member.

Appendix 2: Flow chart and studies selected for the review

Studies selected for review:

Authors, year, country	Design, participants,	Measures, analysis	Outcomes
Bergner, Leiner, Carter, Franz, Thompson, & Compton (2008), USA	-Qualitative -12 family members of 10 inpatients (age 18-28 years) experiencing FEP	Thematic analysis	Four themes emerged as informative of the period of untreated psychosis before treatment initiation: (1) misattribution of symptoms or problem behaviours (e.g., depression, drug use, and adolescent rebellion), (2) positive symptoms causing unusual or dangerous behaviours that served as a catalyst for initiating treatment, (3) views about personal autonomy of an adult or nearly adult patient, and (4) system-level factors (e.g., unaffordability of health care and inefficiency on the part of health care providers).
Boydell, Gladstone, & Volpe (2006), Canada	-Qualitative	Interpretive interactionist framework	Two themes were identified: (1) Ignoring signs and symptoms of psychosis and attempting to hide these from others, (2) Persuasive and coercive elements of others in help-seeking.
Cadario, Stanton, Nicholls, Crengle, Wouldes, Gillard, & Merry (2011), New Zealand	-Qualitative -12 young people experiencing FEP (age 15-18 years), 12 primary caregivers -	General inductive approach	Six themes were identified: (1) difficulties noticed, (2) lack of awareness of mental illness, (3) how help was sought, and which service was approached, (4) thoughts about illness precipitants, (5) experience of services and suggestions, and (6) beliefs and knowledge of mental illness. Both similarities and differences were found throughout the themes between adolescents and carers.
Corcoran, Gerson, Sills-Shahar, Nickou, McGlashan, Malaspina, & Davidson (2007), USA	-Qualitative -13 family members of outpatients with FEP (aged 16-24)	Phenomenologically Based Approach	Five themes were identified: (1) social withdrawal and mood symptoms occurred in essentially normal but vulnerable adolescents, (2) attributions included typical adolescence, stress and drugs, and families coped through persuasion and prayer and sought help within their social networks, (3) frequently a crisis or escalation in symptoms which then provoked entry into the mental health system; (4) dissatisfaction with available services, (5) diminished expectations for the future.
Czuchta, & McCay (2001), Canada	-Mixed methods -20 family parents of people experiencing FEP (age 18-35 years)	The Social Response Questionnaire (SRQ), Thresholds Parental Burden Scale, Mishel Uncertainty in Illness Scale-Parent/Child	Quantitative findings indicated; (1) as stigmatized attitudes towards mental illness and feelings of ambiguity increased, so did burden; (2) as parental education increased, uncertainty regarding their child's illness decreased; (3) as the number of symptoms causing distress increased so did burden and lack of clarity regarding their child's illness. A significant amount of time passed before parents were able to access help. No relationships were found

		<p>Form, Help-Seeking Indicators(1) number of attempts to seek help; 2) length of time from first noticeable sign and symptom to seeking nonhealth professional help; 3)length of time from first noticeable sign and symptom to seeking psychiatric help.</p> <p>Thematic analysis</p>	<p>between indicators of parental help-seeking and the study variables. A subset of five participants described their help-seeking experience. Three themes found: (1) Evolving change: What does it mean? (2) Continuous help-seeking, and (3) The help-seeking experience: Impact on parents</p>
de Haan, Welborn, Krikke, & Linszen (2004), Netherlands	-Quantitative -61 mothers of inpatients (aged 18-27) experiencing FEP	<p>Researcher designed questionnaire asking: (1) What did you think was the matter when you first noticed psychotic symptoms in your child? (2) What was the main reason for which you thought psychiatric treatment was necessary? (3) What obstacles did you perceive in initiating psychiatric treatment? (4) Do you have any advice or suggestions for caregivers</p>	<p>11.5 % thought their child's difficulties were psychosis, 27.9% thought their child's difficulties were another mental disorder, 31.1% thought changes were caused by use of street drugs.</p> <p>32.8% of the mothers thought that the reluctance of patients to acknowledge that they needed help was the major obstacle in initiating psychiatric treatment.</p> <p>54% of the mothers perceived factors related to the delivery of professional care as problems in initiating psychiatric treatment.</p>

		on how they could facilitate an early start of treatment?	
Franz, Carter, Leiner, Bergner, Thompson, & Compton (2010), USA	-Qualitative -12 family members of individuals with FEP(mean 22 years)	Grounded theory	Four themes: (1) society's beliefs about mental illnesses; (2) families' beliefs about mental illnesses; (3) fear of the label of a mental illness; and (4) a raised threshold for the initiation of treatment. A grounded theory model was developed as a schematic representation of the themes and subthemes uncovered in the family members' narratives.
Haley, Drake, Bentall, & Lewis (2003), UK	-Quantitative -47 inpatients with FEP (mean age 29 years), 49 control participants with diabetes, 51 normal controls	Multidimensional Health Locus of Control (MHLC) scales, Duration of Untreated Psychosis(measured as described by Larsen, 1998), The Drug Attitudes Inventory	Schizophrenia patients, both at first episode and 18 months later, had a pattern of health beliefs that was similar to those of the patients with diabetes and significantly different to the normal controls. There were significant associations between internal locus of control score and short DUP, and between external locus of control score and a positive attitude to medication as measured by the Drug Attitudes Inventory.
Hardy, Dickson, & Morrison (2009), UK	-Qualitative -10 individuals with FEP (aged 16-30)	Thematic analysis	Three themes: (1) perception of needs, which highlighted how participants recognized the need to enter services and how they identified what they required from the service; (2) participants' subjective journey; and (3) participants' orientation to the future.
Judge, Estroff, Perkins, & Penn (2008), USA	-Qualitative -15 individuals with FEP (mean age 24.4 years)	Grounded theory Content analysis	Two over-arching categories: (1) Recognizing changes, refers to alterations that individuals observed in themselves during early psychosis and how they identified and made sense of these changes, (2) responding to changes and encompasses themes, relating to how individuals responded to psychosis-related changes in the self.
Knight, Wykes, & Hayward, P (2003), UK	-Qualitative -6 participants with diagnoses of schizophrenia (mean age 31 years)	Interpretative Phenomenological Analysis	Three themes: (1)judgement, (2) comparison, and (3)personal understanding of the (mental health) issue. Stigma was evident both as public-stigma and as self-stigma.
Monteiro, Dos Santos, & Martin (2006), Brazil	-Qualitative -12 relatives of outpatients with	Data grouped into categories, concepts and notions as	Themes were identified relating to: 1) the relatives' stereotyped misconceptions about mental illness; 2) models constructed to understand the patient's problem; 3) fear of psychiatric treatment;

	FEP(aged 20-29 years)	proposed by Lalande (1960)	4) a bad experience with psychiatric services.
Skeate, Jackson, Birchwood, & Jones (2002), UK	-Quantitative -42 FEP participants (Mean age 22)	Miller Behavioral Style Scale, Multi-dimensional Health Locus of Control (HLC) scale, measures of DUP, and GP attendance.	Shorter DUP was associated with more frequent GP attendance in the 6 years before the onset of psychosis and lower health threat avoidant coping scores. Early psychosis sample had a lower internal HLC mean score and higher chance and 'powerful others' HLC mean scores compared with other samples.
Tanskanen, Morant, Hinton, Lloyd-Evans, Crosby, Killaspy, Raine, Pilling, & Johnson (2011), UK	-Qualitative -21 participants with FEP(mean age 26.5), 9 carers.	Thematic analysis	Themes found were: 1) Understandings of symptoms and experiences, 2) Help-seeking processes; 3) Beliefs and knowledge about mental health services; 4) Responses of social networks to illness onset and help-seeking; 5) Health professionals' responses
Wong, Davidson, Anglin, Link, Gerson, Malaspina, McGlashan & Corcoran (2009), USA	-Quantitative -Family members of 11 individuals at clinical high risk, of 9 patients with FEP(mean age 15.9 years)	Opinions about Mental Illness scale, The Family Experiences Interview Schedule	The level of stigma was low, families endorsed many supportive statements, for example, patients should be encouraged to vote, patients want to work, mental illness should be protected legally as a disability and parity should exist in insurance coverage. Families also endorsed that both talking and a belief in God and prayer can help someone get better. Only ethnic minority families of individuals with recent-onset psychosis endorsed a sense of shame and need to conceal the patient's illness.
Wright, Harris, Wiggers, Jorm, Cotton, Harrigan, & McGorry (2005), Australia	-Quantitative -1027 young people aged 12-25 years	-Researcher designed mental health literacy questionnaire.	Almost half the respondents were able to identify depression correctly, a quarter identified psychosis correctly. Counsellors and family or friends were the most commonly cited forms of best help, with family or friends preferred by the younger age group for depression. General practitioners were considered more helpful for depression, and psychiatrists and psychologists more helpful for psychosis. Most respondents considered counselling and psychotherapy to be helpful. More than half the respondents expressed negative or equivocal views regarding the helpfulness of recommended pharmacological treatments.

Wright, Jorm, Harris, & McGorry (2007), Australia	-Quantitative -1027 young people aged 12-25 years	Researcher defined interview, used vignettes of a young person with either depression or psychosis followed by a series of questions related to recognition of disorder and recommended forms of help and treatment.	Identification of the disorder was the predictor variable most frequently associated with choice of appropriate help and treatment for both the depression and psychosis vignettes. In regard to self-help preferences, correct labelling of the depression vignette was only associated with being less likely to recommend smoking marijuana to relax. Correct labelling of the psychosis vignette, or labelling it as depression, was associated with being less likely to recommend dealing with the problem alone.
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Appendix 3: Participant information sheet



Participant information sheet

Experiences of Help-Seeking

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about the study if you wish.

Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about? The purpose of the study is to find out from service users what may prevent or support people accessing help and what useful information could be communicated to young people about mental health.

Why have I been chosen? We are inviting people who have received interventions from [REDACTED], and who have consented to be contacted regarding this research.

Do I have to take part? It is up to you to decide. We will describe the study and go through this information sheet which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive in any way.

Who is doing the research? Helen Glossop, with support of research supervisors ([REDACTED] and Ms Anne Cooke, Canterbury Christ Church University) is undertaking the research as part of her training to become a clinical psychologist.

Why are we doing the research? We are interested in what helps and hinders help-seeking for mental health difficulties.

What will I have to do? If you decide to take part we will invite you to attend an interview. I will invite you to discuss how you came to access help from mental health services, and what information you suggest could be provided to young people. The interview will be audio-recorded and will last for up to sixty minutes. You will be given the option of whether you would like a service user researcher who works for the NHS present during the interview to ask some of the questions, as some people find this helpful.

Will I incur any expenses by taking part or receive payment? Unfortunately, we cannot provide payment for taking part. However, travel expenses up to the value of £10 will be paid.

What are the possible disadvantages to taking part? There are no immediate disadvantages to taking part. Some people find interviews tiring and may find discussing issues around help-seeking for mental health difficulties hard. The researchers are used to

working and carrying out interviews with people with mental health difficulties. They will therefore work to minimise such distress, and will encourage you to access appropriate support should you become distressed. You will receive the same care whether or not you agree to take part.

What are the possible benefits? Many individuals find it empowering to discuss and share their experiences. In addition the results could help to guide interventions to help young people to seek help as early as possible if and when they need to.

Will my taking part in the study be kept confidential? Yes. All the information which is collected about you during the course of the research will be kept strictly confidential and any information that is stored will have your name removed so that you cannot be recognised. Only in exceptional circumstances, such as if you or someone close to you was at risk of harm in anyway, would information be disclosed. In such situations, any further action would always be discussed with you first.

What will happen if I don't want to carry on with the study? If you decide to withdraw from the study, that is up to you. This includes if you lose capacity to consent to being in the study. It will not affect the care you receive in any way. In this situation we would still like to use the information you have provided to us.

What if there is a problem? If you have any concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (contact number: 01892 507673). If you remain unhappy particularly about the way you have been dealt with during the study then contact [REDACTED]. If you wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained through your care co-ordinator.

What will happen to the results of the study? We intend to publish the results in journals where it will have the most influence. We will also make sure that service users will have access to the results whether or not they took part in the research. You will not be identified in any of these reports.

What will happen to the information I give? The information you give in the interview will be audio-recorded and kept confidentially. All information from the interviews will be destroyed after 10 years from when the project is complete in line with NHS policy.

Who has reviewed this study? All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the [REDACTED] Research Ethics Committee in October 2011.

If you have any questions you can contact Helen on (01892 507673)

Please say your request is for Helen Glossop and
she will get back to you as soon as she can.

Alternatively you can call either of the research supervisors ([REDACTED]
[REDACTED] or Ms Anne Cooke, 01892 507631).

Appendix 4: Consent form



Consent form

Barriers to Help-Seeking

Please put your initials into the box:

1. I confirm that I have read and understood the information sheet dated 01.09.11 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical records and research data collected during the study, may also be looked at by individuals from the sponsor organisation, from regulatory authorities, or from the NHS Trust, where it is relevant to me taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that the information I give will be kept confidential except in exceptional circumstances, if it is revealed that I or someone else is at harm, in which case information will be passed to relevant services. ☐
5. I agree that the interview will be audio-recorded and quotations from me may be used in published reports of the study but I will not be identifiable from these. ☐
6. I agree to take part in this study. ☐

----- Name of participant	----- date	----- signature
----- Name of person taking consent	----- date	----- signature

Appendix 5: Initial Interview schedule

Interview Topic Guide

Introduction- Recap on purpose of the project, procedure

Questions

1) Initial experiences of help-seeking

How did you come to get help from mental health services?

Was there a point at which you needed help? What factors led to this?

I am especially interested in the sort of things that helped you to get some help?

Was there anything that got in the way of you seeking help?

What did you think about getting help? What led to that belief?

What did family think?

Was there anything your family thought about mental health difficulties or seeking-help that influenced you?

What did friends think?

Was there anything your friends thought about mental health difficulties or seeking-help that influenced you?

Conclusion - summary, thanks and debriefing

Appendix 6: Approval letter from ethics committee

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Appendix 7: Trust Research & Development approval letter

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Appendix 8: Abridged research diary

Developing idea

January 2010: We had the research fair at Salomons today and a presentation about research into school based interventions to reduce stigma against people with mental health difficulties really interested me. I spoke with the presenter, she had lots of ideas for developing the project.

February 2010: Met with the potential supervisor, along with two other Salomons trainees to discuss areas of research and our ideas. It seems like a pretty under researched area so there's scope for us all to look at different aspects of this from perspectives of teachers, parents and service users. I suggested I'd like to take on the service user aspect as I have experience in research with people using mental health services. The other two trainees had preference for the other areas so this worked out well.

29th July 2010: Meeting with lead supervisor. I've started thinking about my experiences of how service users may experience stigma. I thought about previous groups I have run and how perceived stigma can be a uniting factor for people in discussion. It makes me wonder whether focus groups may be a valuable way of hearing people's experiences. We discussed having people with different mental health difficulties ('diagnoses') in different groups to share common experiences to try and gain wide perspectives of opinions.

August 2010: Reading ideas on how people of different genders experience stigma differently. I'm wondering if splitting people into groups by gender and by different types of mental health difficulties is too much. I thought it would be best to use some sort of quantitative measure to compare these groups, although I'm feeling that this won't capture the richness of people's experiences. I'm starting to consider solely using a qualitative approach.

10th September 2010: Thinking about my research question and that I'm interested in how stigma acts as a barrier to people receiving professional help, and prevents coping and inclusion. I've been reading qualitative studies of people's experiences of services and recovery in psychosis I'm starting to feel passionately about using a qualitative approach for the research, to explore experiences rather than imposing pre-determined ideas on people as would a quantitative method. This is especially true as the stigma measures I've reviewed weren't designed with young people in mind.

17th September 2010: Meeting with my lead supervisor ahead of IRP proposal. I told her I would prefer to use a qualitative method of data collection to hear people's more subjective experiences. I'm unsure whether IPA or grounded theory would be preferable analysis for the study. It seems I am interested in people's experiences but also want to understand and explain them. I think that grounded theory would be preferable, and could be used to see if categories found are applicable across the different focus groups I will be holding. We talked about research questions as being 'How does stigma act as a barrier to help-seeking, coping and inclusion at first onset of mental health difficulties?' and 'What key themes about mental health could be communicated from a young age to promote more positive beliefs regarding mental health, and enable service users to seek help sooner, to cope better and feel more a part of society?'

October 2010- IRP proposal meeting: I met with Sue and Michael today to discuss my IRP proposal. They feel the research questions need revision to draw more on psychological theory. Reading around makes me realise I am most interested in stigma as a barrier to help-seeking. But

I need to understand more about what self-stigma actually consists of before I can ask people whether it impacted on their help-seeking.

24th November 2010: I'm doing so much research on what stigma is and how it may impact on help-seeking that I'm worried how biased this will make the interpretations for my analysis. I'm not sure how I can use grounded theory if I have preconceived ideas about what I'm looking for. I'm also still feeling worried about building up a grounded theory around heterogeneous groups. I'm feeling worried that I'm still in the mindset of the quantitative research that I've done previously and know I need to step away from 'proving or disproving' existing research. I'm concerned about how my knowledge of previous research that knowledge of public stigma, and self-stigma, may impact negatively on help-seeking may influence my research.

25th November 2010: Meeting with Sue to discuss grounded theory. She makes clear how we can make an explicit set of hypothesis from one group that may then be tested with a second group, and in this way heterogeneous groups can be used within GT. Feeling much more optimistic about how this methodology fits with my research questions.

April 2011 Research Ethics Committee: Ethics have rejected the study, partly because they feel that I'm assuming that self-stigma will be a barrier for everyone. I realise that I've already been blinded by prior research that assumes this to be a barrier for most people. They also suggest running a pilot group to test out my research questions.

May 2011 Pilot group: I am really impressed by how articulately the young people were able to talk about their difficulties in a group together. One realisation from the group was the huge influence other people such as parents, other family, and friends had on them initially accessing help, perhaps emphasised because of the age that they were. Not everyone spoke of 'making a decision' to access help and sometimes it was more suggested that help was needed. It also made me think of help-seeking less as a linear process but as more complex with different environmental and personal factors implicated at different times. No two experiences were the same and I'm wondering how difficult it will be to generate an explanatory theory.

16th May 2011: I feel the ethics queries have left me with more questions than answers. I'm questioning my research questions. I'm starting to think more about the complex help-seeking process and interaction about people's own perspectives of what is going on for them, and the perspectives of others, and how this may influence what is going on for them. I think back to the pilot group and wonder if parents/friends had felt there was nothing wrong and the young person did not need help, would they still have sought professional help independently? The topic guide made sense to me but now I feel I'm picking apart what I'm prompting for and why. I was prompting people for concepts the literature had suggested were implicit in self-stigma such as 'entrapment'. But I wonder whether entrapment would more be something that comes with diagnoses and how implicit it would be in developing a theory of stigma hinders help-seeking.

July 2011 Ethics have given the study a provisional opinion but want a full literature review as they feel there's now not enough information as to what barriers to help-seeking may be and what new information the project will provide.

August 2011- Literature review I've taken my supervisor's advice just to get 'lost' in the literature. Doing so is somewhat liberating as I can explore different concepts without being overly concerned, as I have been previously, that I am straying away from my research questions. It becomes evident that there is some existing literature on help-seeking and diagnoses of anxiety/psychosis. A lot of

the studies on depression and anxiety are using perspectives of people in the general population, and there seems to be information on people that have been 'diagnosed' with these things. One of the reviews evaluates barriers and facilitators to help-seeking for people with depression or anxiety. This makes me realise I've been focusing more on 'barriers' to help-seeking. However, given that the people I will be interviewing have accessed services it will be important to try and uncover which factors may have been important in helping them get access the service.

August 2011 I've decided to focus on psychosis as it seems there is less research on this area and help-seeking. There seems to be a few qualitative studies of families of people with psychosis, and their experiences of help-seeking. It's interesting to read about family perspectives given the literature I've read on stigma from others, and following my thoughts from the pilot group about how it's hard to break away from the impact of others' perspectives. However, I'm left wondering where the voice of the service user is in this area of research. Much of the research with service users seems to explore their initial perceptions of psychosis, but not how they moved past this to think about help-seeking. I think I'm going to amend my research questions to look more specifically at this area. My internal supervisor suggests I focus on reviewing how people's beliefs may affect help-seeking as this is what my research questions focus on. I'm aware from earlier discussions that I need to make sure the focus stays 'psychological' and a focus on beliefs seems to fit with this. It's exciting that with all the time researching and reading I've done is coming together.

October 2011- Ethics Committee Back to ethics, a lot of the panel were different and it felt like we were covering some of the same ground. Fingers crossed.

3rd November 2011 Today I met with both my research supervisors to talk about the next step of my project. We discussed the future timeline for the project and I'm feeling excited about the prospect of getting stuck in to the data collection. We started talking about collecting data from a few individual interviews at a time to allow for some analysis and the questions to change as the categories start being formed. I feel nervous about not being to plan it all ahead as it's very much dependent on what I start to find, but also curious about what people might say.

4th November I got ethics approval through! I feel incredibly relieved that I should be able to stick with the timeline I agreed with my supervisors yesterday.

December 2011 I submit my section A to my supervisors to look at a first draft. It focuses on the beliefs that young people and their families have towards mental health difficulties and help-seeking. It feels like I'm making progress through having such a big section drafted. The concepts I'm talking about like stigma and 'mental health literacy' make sense, however, it keeps entering how different these concepts felt when I was discussing them with young people themselves in the pilot focus group. I need to stay aware that in my interviews with young people that I need to detach somewhat from my ideas influenced by theoretical knowledge about what they've experienced. I need to really listen to their experiences and tailor questions accordingly, while still thinking psychologically about what's been said. A tricky balance!

The R & D process is complete. Feeling a renewed energy and in the new year I'll be able to start a proper on the project.

12 January 2012 I met with my supervisor to discuss the revisions to my section A and data collection. My section A feels like it's nearly there! She feels enthusiastic that we should be able recruit the number of people necessary. I'm feeling excited at the thought of actually talking to

people about their experiences, my interest in the human side of it has kind of been put on hold with the other hoops to jump through and focus on academic side of things so far!

February 2012: Meet with my first two participants. The interviews about their experiences is so interesting, and both are so different. I'm struck by the beliefs these two participants had about absolute isolation when they first start experiencing psychosis. One of the participants in particular also talked inadvertently about losses. While I've been focusing on the benefits of accessing services in terms of the evidence base for early intervention, I get a real sense of the costs of deciding to seek help in terms of losing relationships and future employment opportunities.

March 2012: I'm immersing myself in data collection, transcribing and analysing. I felt quite hesitant in coding the data, and progress is slow. I feel nervous in applying codes that allude to concepts I already know are present in the literature, but reading the Charmaz grounded theory is helpful in ways to consider if the concepts help in understanding the data.

(Later in March): I've definitely become more relaxed with coding the data. I'm really getting a feel for the benefits of grounded theory in analysing as you go and being able to explore emerging concepts more directly with people. I met with my internal and external supervisors to look at some of my transcripts and they're in agreement with the codes I've generated. We had a really useful discussion that it's impossible not to have pre-conceptions about ideas in any research, and the importance of keeping memos to understand the development of ideas.

April 2012: Data collection is complete and I feel really happy with the interviews. It's been a real whirlwind, but I've been so impressed with the young people that I've met and their enthusiasm for the research. The analysis is going well but slowly. Analysing my codes and working out the importance of each, and the links is hard work. I met with my supervisor who reminded me to stay true to my research questions and I this is really helpful in starting to sort through the data, and ignoring parts that don't specifically tell me something about the beliefs of young people.

June 2012: Creating the model took a lot more time than I imagined, there was so much data, but I'm getting there! I really want it to do justice for the young people I interviewed but am frustrated that I won't have time to ask for their comments on it. My supervisor has recommended some amendments to simplify the model. I've sent a draft of section B to both my supervisors, and I'm keen for their feedback. I'm not sure how well it all ties together at this stage but am happy with the results section which does feel grounded in the accounts of young people.

July 2012: It's all starting to come together. I'm making final amendments to sections A and B, and making sure they tie together as they were written so far apart. I anticipated struggling with section C but it's actually proved a useful way to consolidate my thinking on the project, and has me thinking about how it could be carried forward from here.

Appendix 9: Example of uncoded interview transcript

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Appendix 10: Table of sub-categories, categories and focused codes

	Category	Sub-category	Focused code
1	Beliefs that experiences are normal or abnormal	Beliefs that experiences are normal	<ul style="list-style-type: none"> - changes as part of being a teenager - changes were part of 'natural high' - experiences a result of meditation - experiences due to 'being haunted' - experiences due to taking drugs - experiences normal - experiences onset due to life events - experiences understandable in context (and not 'illness') - experiences due to loneliness - nothing unusual or different
		Beliefs that experiences are not 'normal'	<ul style="list-style-type: none"> - something is wrong or not normal - could have MHD - own experiences signify madness - part of self out of control
		Beliefs that there is a problem	<ul style="list-style-type: none"> - confusion regarding experiences - that need to change current experiences - experiences overwhelming
		Beliefs that one is unable to cope with experiences	<ul style="list-style-type: none"> - could not cope with experience - help needed
		Beliefs that services are not necessary	<ul style="list-style-type: none"> - services not necessary - experiences do not signify MHD - difficulties temporary

2	Beliefs about the process of help-seeking	<p>Beliefs that it will be difficult to tell someone</p> <p>Beliefs that it is safe to disclose experiences</p> <p>Beliefs that others will respond negatively</p>	<ul style="list-style-type: none"> - difficult to articulate experiences to others - need to feel right time right to tell someone - need to tell someone who will listen - 'permission' needed to share experiences - whether person telling will understand is important - you can trust the person you're telling - others won't judge you - would be useful to talk to someone experiencing similar - family, partner, peers or tutor can be relied on for support - others may judge you - experiences make you socially unacceptable - if you tell someone their response is unpredictable - others would not be able to help - talking about it would be stigmatising - telling people is 'attention seeking' - would not be believed or taken seriously - others are persecuting you
3	Beliefs about the outcome of help-seeking	Beliefs that help-seeking will have negative consequences for oneself	<ul style="list-style-type: none"> - telling people may lead to losses - telling someone may have negative consequences - telling someone may result in getting locked up - telling someone would change identity

	Beliefs about the outcome of help-seeking (continued)	<p>Beliefs that disclosing experiences will relieve current distress of family</p> <p>Beliefs that through disclosing the young person will become a burden to their family</p> <p>Belief change is possible</p> <p>Beliefs that one is unhelpable</p> <p>Beliefs that services could provide help</p>	<ul style="list-style-type: none"> - (no focused code) - (no focused codes) - Help-seeking is a possibility that difficulties could be overcome - (no focused codes) - services can be helpful (as seen them be helpful for others) - services may help with difficulties or provide answers - medication could be helpful
4	<i>Perceptions of others beliefs about experiences as normal or abnormal</i>	<i>Beliefs that others believe that the young person's behaviour is normal</i>	<ul style="list-style-type: none"> - <i>other belief that YP behaviours due to drug use</i> - <i>other belief that YP behaviours due to life events</i> - <i>other belief that YP behaviours due to overuse of medication</i> - <i>other belief that YP behaviours due to being 'angry'</i> - <i>other (parent) belief that YP behaviour due to other parent</i> - <i>other belief that YP behaviours due to typical teenage development</i> - <i>other belief that behaviours due to YP due to watching weight</i> - <i>other belief that YP will get over behaviour in time</i> - <i>other belief that YP not 'ill'</i> - <i>other belief that YP's behaviour changes part of normal development</i>

		<p><i>Beliefs that others believe that the young persons' behaviour is not normal</i></p> <p><i>Beliefs that others believe that something has changed for young person</i></p> <p><i>Beliefs that others believe that that young person needs professional help</i></p>	<ul style="list-style-type: none"> - <i>other belief that YP behaviour due to attention seeking</i> - <i>other beliefs that YP behaviours are worrying or scary</i> - <i>belief that YP may be labelled</i> - <i>(no focused code)</i> - <i>young person may be at risk, need protecting</i> - <i>parent cannot do enough to help on their own</i>
5	<i>Perceptions of others beliefs about the outcome of help-seeking</i>	<p><i>Beliefs that others believe that service use will have negative outcomes</i></p> <p><i>Beliefs that others believe that services will be helpful</i></p>	<ul style="list-style-type: none"> - <i>psychiatric ward negative</i> - <i>young person may be taken away</i> - - <i>(no focused codes)</i>
6	<i>Existing beliefs about MHDs</i>	<p><i>Beliefs that MHDs are understandable</i></p> <p><i>Beliefs that MHDs are socially undesirable</i></p> <p><i>Beliefs that MHDs do not affect young people</i></p>	<ul style="list-style-type: none"> - <i>MHD caused by chemical</i> - <i>MHD hereditary</i> - <i>MHDs more understandable if you know someone who has experienced them</i> - <i>MHD is a weakness</i> - <i>MHD something to be feared</i> - <i>people with MHDs experience bad or scary symptoms</i> - <i>people with MHDs 'mad'</i> - <i>people with MHDs should be avoided</i> - <i>people with MHDs would be locked away</i>

7	<i>Beliefs about the impact of experiences on the self</i>	<i>Beliefs that experience mean something bad about oneself</i> <i>Beliefs about isolation</i>	<ul style="list-style-type: none">- <i>you are unacceptable (odd, damaged, failure, weak)</i>- <i>not worth help</i> - <i>that there is no one to talk to</i>- <i>other were not interested in their difficulties</i>- <i>others do not have similar experiences</i>- <i>should deal with difficulties on your own</i>
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Appendix 11: Example quotes for category

Category: **Beliefs about the process of help-seeking**

(Some additional content is included to provide context for comments)

Sub-category	Focused Code	Quotes
Beliefs that it will be difficult to tell someone	- difficult to articulate experiences to others	<p><u>Participant 10 Transcription</u></p> <p>Reference 1</p> <p><i>P: Just explaining why you feel depressed, the only thing was I could think of was thinking about the feeling that I'm getting, but it was a lot easier for people to say I feel depressed because I've split up with my partner or because this happened, but there was no real reasons apart from this feeling that I've had and was enabling me not to do things. It's actually quite hard, and I think it still is now, to say how it affects you and why, why it does that.</i></p> <p>Reference 2</p> <p><i>P: Yeah it was hard, I remember feeling a little bit tearful about telling them how hard it was and trying to explain then how far you'd come.</i></p> <p><u>Participant 4 Transcription</u></p> <p>Reference 1</p> <p><i>P: I remember erm, trying to explain it to my mum but the words didn't really come much</i></p> <p>Reference 2</p> <p><i>P: Hard, yeah it was the first person I'd ever actually properly spoken to about it.</i></p> <p>Reference 3</p> <p><i>P: Little bits and bobs, I tried to get across but obviously didn't.</i></p> <p><u>Participant 5 Transcription</u></p> <p>Reference 1</p> <p><i>P: Yeah, of course I wanted to tell people but at the same time I couldn't tell people, but you know, the biggest thing for me was that I couldn't differentiate between reality and what was in my head.</i></p> <p><u>Participant 7 Transcription</u></p> <p>Reference 1</p> <p><i>I felt very rushed, I couldn't really get my thoughts</i></p>

		<p>together. It takes a while you know, especially when you're with somebody you don't know and you're going through something very new and very personal, it takes a while to build up courage to say the things you need to say.</p>
	<ul style="list-style-type: none"> - need to feel right time to tell someone 	<p><u>Participant 12 Transcription</u></p> <p>Reference 1 it wasn't the right time to tell mum, she was just getting over it,</p> <p>Reference 2 So I did think by telling her, I just wasn't ready before, I wasn't clear. And like March time I was like ready to tell her and I didn't think it would go too bad and she's gonna think I'm not mad.</p> <p>Reference 3 there was never a right time. I couldn't just take her on the sofa and say oh I've been experiencing this from about fourteen to fifteen, she'd be like, you're joking, so there was never ever a right time, like she's so busy,</p> <p><u>Participant 5 Transcription</u></p> <p>Reference 1 I wasn't ready to talk about it either</p> <p>Reference 2 but the biggest thing is no one can help you, until you want to help yourself.</p> <p>Reference 3 And then I went to go see my GP on my own and it was me this time, not my mum pushing me.</p> <p>Reference 4 when I first went to he GP than when I went to the GP on my own, I was more ready to talk about what I was going through</p>
Beliefs that it is safe to disclose experiences	<ul style="list-style-type: none"> - need to tell someone who will listen 	<p><u>Participant 4 Transcription</u></p> <p>Sometimes just what you need, you just want to feel like someone is there and does actually want to listen to the crap you're about to tell them and not just turn away and say, oh dear.</p>

		<p><u>Participant 6 Transcription</u></p> <p>Reference 1</p> <p><i>he listens, that's, and I didn't think anyone was actually listening to what I was saying when I was sectioned, even my parents didn't really feel like they were listening</i></p>
	- 'permission' needed to share experiences	<p><u>Participant 11 Transcription</u></p> <p>Reference 1</p> <p><i>P: Maybe if she'd have asked I'd have told her but she never asked so I didn't really feel like I could tell her.</i></p> <p><u>Participant 2 Transcription</u></p> <p>Reference 1</p> <p><i>none of them really asked so I couldn't really tell what was going on</i></p> <p><u>Participant 3 Transcription</u></p> <p>Reference 1</p> <p><i>P: I think it was harder to talk to people that didn't really want to know about it. Like, the ones that couldn't accept, cos I was living with a girl at the time and erm, she just didn't believe in mental illness at all, she just didn't really believe that it existed, and then I got unwell and I just couldn't talk to her about it cos she just couldn't accept any of it, but with the people that understood they just kind of asked me how I was and how the treatment was going, that kind of thing.</i></p> <p><i>H: Mm hm.</i></p> <p><i>P: So it was easier to start the conversation with them and was easier to talk to them about it.</i></p> <p>Reference 2</p> <p><i>she just doesn't really believe in it kind of thing, so yeah, it was really hard.</i></p> <p><i>H: Yeah, sure, how did you deal with that?</i></p> <p><i>P: Erm, I just kind of avoided the subject with her</i></p> <p>Reference 3</p> <p><i>P: Yeah, yeah, they were really accepting they wouldn't like question it in a way that made it feel like my fault.</i></p> <p><i>H: Mm, hm.</i></p>

		<p><i>P: They were really like open about it and happy to talk about it and stuff. It made it easier to tell them.</i></p> <p>Reference 4</p> <p><i>P: It wasn't really until I got help that I told anyone about it cos the questions got asked, like have you seen anything unusual and I talked to people about it, reluctantly at the time, but I was, it was kind of after.</i></p> <p>Reference 5</p> <p><i>he just straight out asked me why I was in there which I found better than people kind of beating around the bush about it, like trying to get answers out of you but not really saying anything, so it was quite nice and I just asked him, so it was easier to talk to each other about it and stuff.</i></p> <p>Reference 6</p> <p><i>my like really supportive friends would talk to me about it</i></p> <p><u>Participant 4 Transcription</u></p> <p>Reference 1</p> <p><i>P: I suppose erm, I don't know, someone to talk to</i></p> <p>Reference 2</p> <p><i>And she always said that she'd be happy to talk or to help me. So that sort of gives you that little extra thinking of maybe I can tell that person.</i></p> <p><u>Participant 5 Transcription</u></p> <p>Reference 1</p> <p><i>P: Oh God no, if the teacher hadn't have dragged it out of me I wouldn't have approached her.</i></p> <p><u>Participant 7 Transcription</u></p> <p>Reference 1</p> <p><i>I just think they need to be a bit more, because they're so rushed it doesn't really give people chance to speak about what's going on, and I think they need to be a bit more clued up. You know, if someone comes in and says oh I've been feeling depressed and you know, slow and tired and that sort of thing. You know, to maybe, for them to bring up the conversation about mental health, for them</i></p>
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		<p><i>to broach like, are the symptoms like psychosis of behaviour or suicidal thoughts. Someone who's experiencing that for the first time it's really difficult to talk about it so you know, it's better to err on the side of caution and for a doctor to be you know, you said you're feeling depressed but is it possible that you're having other symptoms like this, blah, blah, blah.</i></p> <p>Reference 2 <i>when you're in that situation you need people to reach out to you.</i></p> <p><u>Participant 9 Transcription</u> Reference 1 <i>H: And what was different about that time that you were able to tell her?</i> <i>P: Er, I dunno cos my mum's told me before that she'd been up to like (local suicide spot) and everything before.</i> <i>H: Was that something she told you before that night, that day?</i> <i>P: Yeah, I think I can remember her saying that, and I think that might be what, I dunno, I'm sure I said something to her before I went.</i></p> <p>Reference 2 <i>P: If my mum would have asked I would have thought about telling her.</i></p>
	- whether person telling will understand is important	<p><u>Participant 10 Transcription</u> Reference 1 <i>H: And was it important it was it was her you told?</i> <i>P: Yeah it was important, it was lucky she was understanding so she was a good person to tell.</i></p> <p><u>Participant 11 Transcription</u> Reference 1 <i>I think just having someone that I thought would understand would have been easier</i></p> <p><u>Participant 12 Transcription</u> Reference 1 <i>I especially didn't want to talk to them, they didn't know me</i></p>

		<p><u>Participant 4 Transcription</u></p> <p>Reference 1</p> <p><i>P: Mm, she was my psychology teacher so I suppose after the bad first experience that I'd learnt from I kind of had that sort of impression that she would understand, she's a psychology teacher, and she went to university and did it so I'm hoping that she has kind of a good insight of things and knows stuff so that's always a good thing to know really.</i></p>
	<p>- you can trust the person you're telling</p>	<p><u>Participant 11 Transcription</u></p> <p>Reference 1</p> <p><i>H: So what makes the person you tell an easier person to tell, what helps with that?</i></p> <p><i>P: I think it's just someone you get on with, someone you feel you can trust</i></p> <p><u>Participant 12 Transcription</u></p> <p>Reference 1</p> <p><i>H: So what made it easier then to tell someone about that?</i></p> <p><i>P: Well, I trusted them and they like reassured me</i></p> <p>Reference 2</p> <p><i>I guess you know just find the right time, talk to someone you trust the most</i></p> <p>Reference 3</p> <p><i>I've always trusted my mum, everyone trusts their mum, but I knew whatever I told her she'd just believe it 100 per cent. And it's just gaining that confidence to tell someone and you have to have confidence in that person that you know they'll always do right in you and not, you know, lock you away. And it wasn't until that time that I genuinely thought, ok, I believe it you know, I can finally tell someone.</i></p> <p><u>Participant 4 Transcription</u></p> <p>Reference 1</p> <p><i>I knew lots of stuff about her and I knew that she wouldn't be the type that you'd tell her and then she'd be gossiping about it behind my back to all my other friends.</i></p>

		<p><u>Participant 9 Transcription</u></p> <p>Reference 1</p> <p><i>H: So what was it about him that you thought you'd tell him?</i></p> <p><i>P: Erm, no I've been always close to him, so.</i></p>
	- others won't judge you	<p><u>Participant 4 Transcription</u></p> <p>Reference 1</p> <p><i>H: So what was different about (friend 2 name)?</i></p> <p><i>P: She was my best friends and she didn't judge you, she doesn't judge people.</i></p> <p>Reference 2</p> <p><i>I knew that she wasn't going to go don't be ridiculous or stuff like that.</i></p> <p><u>Participant 6 Transcription</u></p> <p>Reference 1</p> <p><i>P: Yeah, I told my yoga teacher, and Yoga (name) and er, they were like, oh yeah wow, that's great, yeah, nice one. They asked me what the visions were, and Yoga (name) had had some of the same ones, or similar and erm, we just talked about some of the things that can happen in meditation, but erm, when I had the visions it was in between, it was when I was going to bed and I was lying in bed but I was awake but erm, in between, there's just a period where you're quite close to drifting off and erm, still sort of fully awake and that's when I sort of had them, and we just talked about visions in general and what they mean and erm, yeah. Yeah we just talked about the whole subject in general and it was very calm and relaxed and no one thought anyone was mad and it was just like, you could just talk about it and no one would judge you.</i></p> <p><u>Participant 7 Transcription</u></p> <p>Reference 1</p> <p><i>I hid many of the symptoms that I was having cos I was kinda scared. I guess worried about being judged or labelled.</i></p> <p>Reference 2</p> <p><i>I was worried about being labelled or something like that, at the time.</i></p>

		<p>Reference 3</p> <p><i>I didn't really want to recognise it myself and fear of being labelled, erm, or judged in some way, being carted off in a white van or something</i></p>
	<ul style="list-style-type: none"> - would be useful to talk to someone experiencing similar 	<p><u>Participant 1 Transcription</u></p> <p>Reference 1</p> <p><i>P: and...just if I'd have known someone that would have gone thought the same I could have talked to them-</i></p> <p><i>H: Ok-</i></p> <p><i>P: And they could have sort of given me some information or whatever.</i></p>
	<ul style="list-style-type: none"> - family, partner, peers or tutor can be relied on for support 	<p><u>Participant 12 Transcription</u></p> <p>Reference 1</p> <p><i>P: Well if I said like I was ok she'd be like, hmm, are you sure? And she'd make me sit with her in the evenings, rather than sitting up in my room. So, or she'd be like, oh do you want to watch a movie in my room tonight or something like that</i></p> <p>Reference 2</p> <p><i>...she's going to help me, and she's going to get me help and I'm going to get better</i></p> <p><u>Participant 2 Transcription</u></p> <p>Reference 1</p> <p><i>P: Yeah my head of house, he erh, he was the only one that managed to calm me down in situations at school and I'd just be like..if I didn't want to go in my classroom erm when I got to school he's let em sit in his office and do my class work there and then hand it in to my teacher at the end of the day so he'd just be there to talk to and stuff and he was quite nice about it. Didn't treat me any different to anyone else he just wanted to help so that was good.</i></p> <p><u>Participant 4 Transcription</u></p> <p>Reference 1</p> <p><i>H: So what happened after you told (friend 2 name)?</i></p> <p><i>P: Not a lot really, she just sort of listened to what I had to say and said that she wouldn't, you know obviously gossip about it.</i></p>

		<p><u>Participant 5 Transcription</u></p> <p>Reference 1</p> <p><i>I think she was so wanting me to feel better, erm, that she wanted to do anything that would help so she, she fully supported me, I think my dad just kind of, cos my dad just wants to protect me as well, like we've been saying you know, we just want to protect each other, he so wanted to protect me.</i></p> <p>Reference 2</p> <p><i>it came from outside rather than inside that people started challenging the way that I thought, and then I was just like, yeah I can get some help. And actually my mum did it quite a bit as well, challenged the way that I was perceiving myself, challenging the voices, even though I wasn't ready to that yet. You know challenging the voices and saying you can get help.</i></p> <p><u>Participant 6 Transcription</u></p> <p>Reference 1</p> <p><i>I met my friend, and he's a brilliant friend now, and er, I was just like oh man, I think this has been this, I this, and then we had a great chat and we hugged for ages and then I felt really good.</i></p> <p><u>Participant 8 Transcription</u></p> <p>Reference 1</p> <p><i>then my mum rang me like straight after and said, I've just spoken to the doctor, you need to come home, and my mum left work and I went home and mum just sat me down and was like what's the matter? Erm, the doctor's worried about you, let's just go and see somebody just in case like there's a problem, and we can sort it out.</i></p>
Beliefs that others will respond negatively	- others may judge you	<p><u>Participant 7 Transcription</u></p> <p>Reference 1</p> <p><i>I hid many of the symptoms that I was having cos I was kinda scared. I guess worried about being judged or labelled.</i></p> <p>Reference 2</p> <p><i>I was worried about being labelled or something like that, at the time.</i></p>

		<p>Reference 3</p> <p><i>I didn't really want to recognise it myself and fear of being labelled, erm, or judged in some way, being carted off in a white van or something.</i></p>
	<ul style="list-style-type: none"> - experiences make you socially unacceptable 	<p><u>Participant 5 Transcription</u></p> <p>Reference 1</p> <p><i>P: Going to a mental asylum, being taken away from my family. Not being a member of society anymore, not having a future.</i></p> <p><u>Participant 9 Transcription</u></p> <p>Reference 1</p> <p><i>P: Dunno just guess I felt a bit weird, like an outcast.</i></p>
	<ul style="list-style-type: none"> - if you tell someone their response is unpredictable 	<p><u>Participant 1 Transcription</u></p> <p>Reference 1</p> <p><i>H: Were you worried at all what their response might because you were hearing voices?</i></p> <p><i>P: Erm, sorry, erm, yeah, I just didn't know what to expect or anything.</i></p> <p><u>Participant 11 Transcription</u></p> <p>Reference 1</p> <p><i>P: No, I didn't know what she'd think or what she'd do so i just thought I'd keep it a secret.</i></p> <p><u>Participant 2 Transcription</u></p> <p>Reference 1</p> <p><i>P: I was a bit scared at first cos I didn't know what they were going to do</i></p> <p><u>Participant 3 Transcription</u></p> <p>Reference 1</p> <p><i>I think I definitely agree with like you can't really mention, although I talk about it with my friends it is hard to mention to people that I know don't know about it. Erm, cos you never know quite how they're going to react.</i></p> <p>Reference 2</p> <p><i>you never know quite how people are going to react to it, that's the main worry.</i></p>

	<p>- others would not be able to help</p>	<p><u>Participant 12 Transcription</u></p> <p>Reference 1 <i>I didn't think anyone would be able to understand to be honest cos we'd never had anything like this in our family before, what I knew of anyway, so I didn't think there was any help or way out for it,</i></p> <p>Reference 2 <i>I genuinely didn't think that people would understand</i></p> <p><u>Participant 4 Transcription</u></p> <p>Reference 1 <i>what are they really going to be able to do about it?</i></p> <p>Reference 2 <i>I didn't really see how they could help me</i></p> <p>Reference 3 <i>I still didn't tell anyone for a long, long time I just kept it to myself thinking maybe I'm wrong going to the doctors, like what can the doctors do really and probably thinking that the doctors wouldn't do anything anyway.</i></p> <p><u>Participant 5 Transcription</u></p> <p>Reference 1 <i>P: Cos I couldn't, in my own head I couldn't even work out was going, why would someone else know what was going on.</i></p> <p>Reference 2 <i>P: To be honest, no I had very low expectations. I didn't think anything would happen to be honest, I didn't think that I would get any help, that I was helpable.</i></p> <p>Reference 3 <i>P: I think like I was saying you know it was like black and white, irrational thoughts, thinking you know you're not going to get any help, you're beyond help, you should I just end it now you know, you'll waste everybody's time.</i></p>
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		<p><u>Participant 7 Transcription</u></p> <p>Reference 1</p> <p><i>I felt very strongly that other people couldn't really understand the way that I was feeling.</i></p> <p>Reference 2</p> <p><i>It got to the point where I thought I was you know, a hopeless case, a lost cause type thing. So I guess at that point I wasn't even thinking about you know mental illness, it was, it was just a very painful situation where I felt I was totally beyond help I guess in some way.</i></p> <p><u>Participant 8 Transcription</u></p> <p>Reference 1</p> <p><i>She said oh it might just be good to have someone to talk to, and I think there was there way of saying let's just go so that you can speak to them but at the time, I just thought they were trying to get me some answers as to why I was so angry and I couldn't understand how a doctor could give me that, yeah it was all just really confusing for me, but yeah, I didn't go so.</i></p> <p><u>Participant 9 Transcription</u></p> <p>Reference 1</p> <p><i>my dad's wife, er, she tried speaking to me about it once but I just don't like listening to her in general, er, I dunno, just that side of the family just aren't helpful in general.</i></p>
	- talking about it would be stigmatising	<p><u>Participant 10 Transcription</u></p> <p>Reference 1</p> <p><i>H: And what did you think might happen if you told people about those things that were a bit more bizarre?</i></p> <p><i>P: That they'll think you're a different person, but a lot of it's paranoia about thinking people are staring at you, or thinking things about you, so when you say your symptoms, you kinda think that they'll think even less of you so it's like a weird, vicious circle.</i></p> <p><u>Participant 11 Transcription</u></p> <p>Reference 1</p> <p><i>P: They did lessons on it at school, they covered over</i></p>

		<p><i>it briefly in citizenship, and the thing that made me feel bad is when that lesson was going on and everyone was making jokes about it and I was kind of sat there thinking, what do I do.</i></p> <p>Reference 2</p> <p><i>P: I think what would help I think, if they did lessons on it like covered it at school, actually I was wrong we did do a lesson on schizophrenia at school where we did, like learning about hearing voices where you have people standing each side of people, and I knew that's what I was experiencing but I thought the way everyone was joking about it I thought I could never tell anyone cos there's such a stigma attached to it. I suddenly thought there's a huge, like everyone thinks it's funny and I would never be able to open up to anyone about it, because of the attitude in the lesson it made me feel like I couldn't tell anyone as well. Cos I saw everyone in the classes attitude towards it. I just thought, how am I gonna.</i></p> <p>Reference 3</p> <p><i>P: The teacher seemed like she didn't want to talk about it. She like skimmed over it quite quickly. So it seemed like she felt awkward about it I think. And that kind of made me feel like I couldn't tell a teacher cos they're obviously all like that about it. So I think if it is taught about in classes at school people need to be quite careful cos sometimes they can just make it look like there's a huge stigma attached to it.</i></p> <p><u>Participant 12 Transcription</u></p> <p>Reference 1</p> <p><i>...about people getting locked up cos they've got like schizophrenia and things like that, I didn't know much about it but there was a girl at my school who had it and like everyone bullied her.</i></p> <p>Reference 2</p> <p><i>P: Oh they just laughed at her, she didn't have any friends after that, they'd make her jump, they'd like whisper things in her ear, erm, no people were generally just really horrible to her, she was only in a couple of my classes but I'd see like things stuck to her back like signs and things like freak, people call her freak all the time. So I was like, oh my God I'm</i></p>
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		<p><i>not telling anyone, ever. And I knew, she didn't want to leave school either, so I had the option to leave school.</i></p> <p><u>Participant 2 Transcription</u></p> <p>Reference 1</p> <p><i>There's a lot of stigma around it and but I've never learned anything about mental health at school in my life and I think that maybe if they teach it more even in science or biology or something like that, like the way the brain works and what can effect it if it goes wrong and if they teach more people about it then more people will have an understanding and they won't think you're weird if you go oh I've got mental health problems, or they hear that you've got mental health problems.</i></p> <p><u>Participant 5 Transcription</u></p> <p>Reference 1</p> <p><i>P: Yeah I mean school would be ok, but I think there's still so much stigma around it, especially at secondary school, that you kind of don't talk about it.</i></p> <p>Reference 2</p> <p><i>P: That you were a freak, to be honest I found that at secondary school that if you didn't fit in the box then there was something wrong with you, and then if there was something actually wrong with you, I mean, I say wrong in inverted comers, erm, that was even worse and you would get picked on.</i></p> <p><u>Participant 8 Transcription</u></p> <p>Reference 1</p> <p><i>With me it's a bit different cos I'm young and I've got like a massive social group and then they have another social group and word spreads and people talk and then people change rumours and things so for me it was like everyone's going to be saying that I'm mental and crazy and stuff.</i></p> <p><u>Participant 9 Transcription</u></p> <p>Reference 1</p> <p><i>Another thing is that you know you've still got all these people that blame people with mental health problems, they blame them for all these killings and everything else that people do, and I just felt like I</i></p>
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		<p><i>was gonna be another one of them that people would be like, he's gonna do something, he's gonna do something.</i></p> <p>Reference 2 <i>I always thought, well I still think now that they see people with mental health problems as bad</i></p>
	<p>- telling people is 'attention seeking'</p>	<p><u>Participant 1 Transcription</u> Reference 1 <i>P: Er, I think they thought I was just attention seeking.</i> <i>H: Right, and how did that impact on your beliefs about what was going on?</i> <i>P: Just made me feel worse.</i> <i>H: And did that have any impact on your beliefs about seeking help.</i> <i>P: Mm, yeah it meant that I didn't really want to try and get the help</i></p> <p><u>Participant 11 Transcription</u> Reference 1 <i>P: Cos there was a girl at school that had mental health difficulties, and she used to go round telling everyone all her problems and like, when she cut herself she'd go round and show everyone all the cuts, so it kind of made me think attention seeking at first cos I thought of her cos she went round telling everyone she had mental health difficulties and she was the biggest attention seeker I'd ever come across.</i></p> <p>Reference 2 <i>P: I thought people would just think I was the same as her. Cos basically everyone was saying behind her back, oh she's an attention seeker, I thought if people found out about mine then they would say the same thing. Cos that's what it's kind of seen of in school.</i></p> <p>Reference 3 <i>P: There wasn't a lot of information about it. I knew about self harming, and I knew about kind of depression cos they were out in the open and you had the odd attention seeker at school that would go round telling everyone that they had those problems.</i></p>

	<p>- would not be believed or taken seriously</p>	<p><u>Participant 11 Transcription</u></p> <p>Reference 1 <i>I didn't think anyone would take me seriously.</i></p> <p>Reference 2 <i>P: I didn't think they'd believe me, after the way they treated me I didn't think they'd believe me. I thought they'd probably say, oh you're making excuses to deal with your behaviour. Which is most likely what she probably would have done.</i></p> <p>Reference 3 <i>P: I think I was just too scared that I wouldn't be believed?</i></p> <p>Reference 4 <i>P: It kind of made me think that people obviously think it's just a joke, so why would I tell anyone?</i></p> <p><u>Participant 12 Transcription</u></p> <p>Reference 1 <i>Just what might happen, and obviously the voices telling me you won't get anywhere and they won't take you seriously, and that sort of stuff.</i></p> <p>Reference 2 <i>Obviously the service she got were absolutely useless, she went to see her doctor he didn't want to know, she went to the hospital they didn't want to know, they said that she was making it up and I thought like people might not be able to believe me. Like the doctors didn't believe her.</i></p> <p>Reference 3 <i>P: Oh it was really hard cos you know, if you have a broken arm people can see it and they'll believe it but something inside, then it's a lot harder to believe.</i></p> <p><u>Participant 4 Transcription</u></p> <p>Reference 1 <i>But my mum wouldn't really understand she'd just probably say you were just dreaming, you know.</i></p>
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	<p>- others are persecuting you</p>	<p><u>Participant 2 Transcription</u></p> <p>Reference 1 <i>Most of the time I just thought everyone was against me sort of thing so shutting myself out didn't really help.</i></p> <p>Reference 2 <i>I couldn't I was scared if I went outside and saw an ambulance coming past I thought they were coming to get me sort of thing every time.</i></p> <p>Reference 3 <i>P: I used to hear horrible things like they'd tell me things like horrible about what my family were saying behind my back sort of thing. None of it was true but I didn't know that at the time I just believed what I was hearing sort of thing.</i></p> <p><u>Participant 3 Transcription</u></p> <p>Reference 1 <i>There were times when I saw things and heard things that weren't there and the paranoia I experienced especially regarding (name of partner), being violent towards (name of partner).</i></p> <p>Reference 2 <i>P: Cos I think I was quite paranoid and I thought that they were all against me, I remember thinking that, but then with the medication they were trying to control me, one of my big things was that they were trying to control me with medication.</i></p> <p>Reference 3 <i>I thought that she'd locked me in the house and that she was trying to control me so I didn't really want to talk to her about anything.</i></p> <p>Reference 4 <i>He was still there for and supported me and stuff but I felt the same about him, I was probably even more paranoid about him.</i></p> <p><u>Participant 4 Transcription</u></p> <p>Reference 1 <i>I didn't really see how they could help me, or what they could do and I became paranoid of them anyway.</i></p>
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		<p>Reference 2</p> <p><i>I was paranoid that my friends were talking behind my back, that they weren't actually my friends and that people, certain people became quite distinct, people that were properly following me and they eventually got given their names and I started believing that they were there to take me away or stuff like that.</i></p> <p><u>Participant 8 Transcription</u></p> <p>Reference 1</p> <p><i>I don't know really, at the time it was all just like a massive blur, like everyday merged into one, erm, but because of all my symptoms like my paranoia and stuff I just thought that it was like my step-dad and it was all linked together and they were all just doing it to me and at some points I thought that I was the only normal one and everyone else was going mad around me and that made me think oh actually it's me cos everyone else is normal.</i></p> <p>Reference 2</p> <p><i>It was really difficult with my step-dad because erm, we, he was like the main thing in my little world at that time, like everything that happened I blamed him. Like I was really paranoid about it, like I'd start a row with him and like my mum would come downstairs and I'd say he started it, and then he would say no it's you, so I'd say right you're out to get me, so it was a really hard relationship with him at the time cos he's done nothing wrong.</i></p>
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Appendix 12: Samples of coding memos

Excerpt of developments in code of 'permission' needed to share experiences'

After participant 2 interview:

Context in which people make it difficult to tell

Pt 2: Erm, I just thought well he was in the army for a long time so he had quite strict instructions to do and erm you could never give in sort of thing so by me having mental health problems it meant that I was giving up and erm, that's what I kept thinking oh I've given up, I've failed sort of thing. And then cos I kept thinking that it made my mood go even lower than it already was and I didn't...I stopped talking-to o my granddad just because he had said that.

With this and with participant 3 other people appear to create an environment in which it's not permissive to disclose difficulties. I wonder if this could be related to others' denial, or inability to bear that a relative or friend could have a mental health difficulty. Different projections from others are described; that people may have 'failed', that people may to blame, that they didn't think mental health 'existed'.

Could also link with code of 'protecting oneself from loss', if there is a context others have created in which it is not safe to talk about your difficulties to others why is that, what is to be lost if you do. For pt 2 it is a strong relationship with his grandfather. For pt 3 what is dangerous....the fear of not being believed/ understood/taken seriously? Changing social relationships? Stigma...or is this borrowing too much from the literature and my assumption, is it more simply negative responses from other due to fear/lack of knowledge etc., rather than discriminatory?

After pt 9 interview:

People sharing something difficult about their experience being permissive

I'm especially thinking about pt 9 for this one:

H: And what was different about that time that you were able to tell her?

P: Er, I dunno cos my mum told me that she'd been up to like (place name of popular local suicide spot) and everything before.

It's saying 'I've experienced something like this too', making it permissive that this does happen and therefore reducing isolation? Therefore isolation could also exist as a 'non-permissive environment'. I wonder in this particular example if this links into the code about 'protecting others'. This participant was pretty isolated, was bullied at school, and did not strong links with family. He couldn't contemplate talk to his mum about his experiences. His mum was his main support and so in not telling her what was happening may partially have been protecting her. But her sharing experiences made it more permissive for him to share his and no longer feel he had to protect her from it?

Developing codes:

15.03.12 Being asked

The 'permission giving' code makes me think about the J.Read literature about the need for professionals to ask patients whether they've experienced abuse, that is that a lot of people won't say they've experienced abuse unless asked by health care professionals. This seems to echo in what

some of the young people are saying about their unusual psychosis experiences. People express this in different ways. Participant 2 really explicitly stated that people didn't ask and therefore he couldn't tell them what was going on, implying that if someone had asked then this would have made it easier. Therefore if people don't mention this in future interviews it could add to the data to out what may have been more permission giving (or made it easier) to disclose?

Excerpt of developments in code of 'negative self experiences'

05.04.12

P5: Erm, I kind of thought everyone with mental health issues were lunatics which obviously didn't help my perception of myself.

The first participant to clearly illustrate self-stigma, that is to state a perception of people with mental health difficulties and start to apply it to themselves. This ties in with the comments from noticing negative things about themselves, that is most participants have spoken about viewing themselves negatively. Yet it feels somewhat distinct. The others so far haven't necessarily linked this in with perceptions of themselves as having a mental health difficulty.

24.04.12

H: So what got in the way of telling someone?

P9: I don't really tell anyone anything. Keep everything bottled up.

H: And what gets in the way of that do you think?

P9: Nothing really, I just things people, I think everyone should come before me, I think that everyone's better off without knowing everything I go through so I just leave it.

This is interesting, although it does fit in 'negative perception of self' code it may also relate to not thinking they deserved help? Thinking everyone should come before me, it would have been useful to explore this more. I wonder if there was something of this in other pts, e.g. pt 5 states not wanting to burden her parents due to the difficulties they were already experiencing, pt.7 not wanting to cause stress to his parents. Could be protecting people? Or not thinking other will be able to cope if you tell them? On a deeper level not being contained? Or it could be related to family styles of dealing with problems, pt 9 illustrates elsewhere that his family don't talk to each other about their difficulties, that this would not be seen as acceptable. Which is an inference for what he thinks others may believe about disclosing difficulties. I need to explore further such inferences in the last few interviews to shape the category further.

25.05.12- Linking negative self-beliefs with help-seeking

1) *Pre-disposed with 'being different'*. Start with pt 12 who feels like she's always been the odd one out, therefore reporting her difficulties would make her stand out more. Fits with quite a few of the pts report being bullied. Some the people that were bullied also had the influence of the voices on telling people that they were not good enough and they would not be believed. So both parts above about beliefs about self could be reinforced if you help seek, you already think that you're not good enough, there's something less about you because you've always felt it or bullies have made you feel that way, then the voices join in and leads to beliefs that if you tell someone you will not be believed or taken seriously or even that you are not worth the help.

- 2) There seems to be some other types of negative beliefs emerging that to have these difficulties, means you have failed, means you are weak. Does this fit more in with the self-

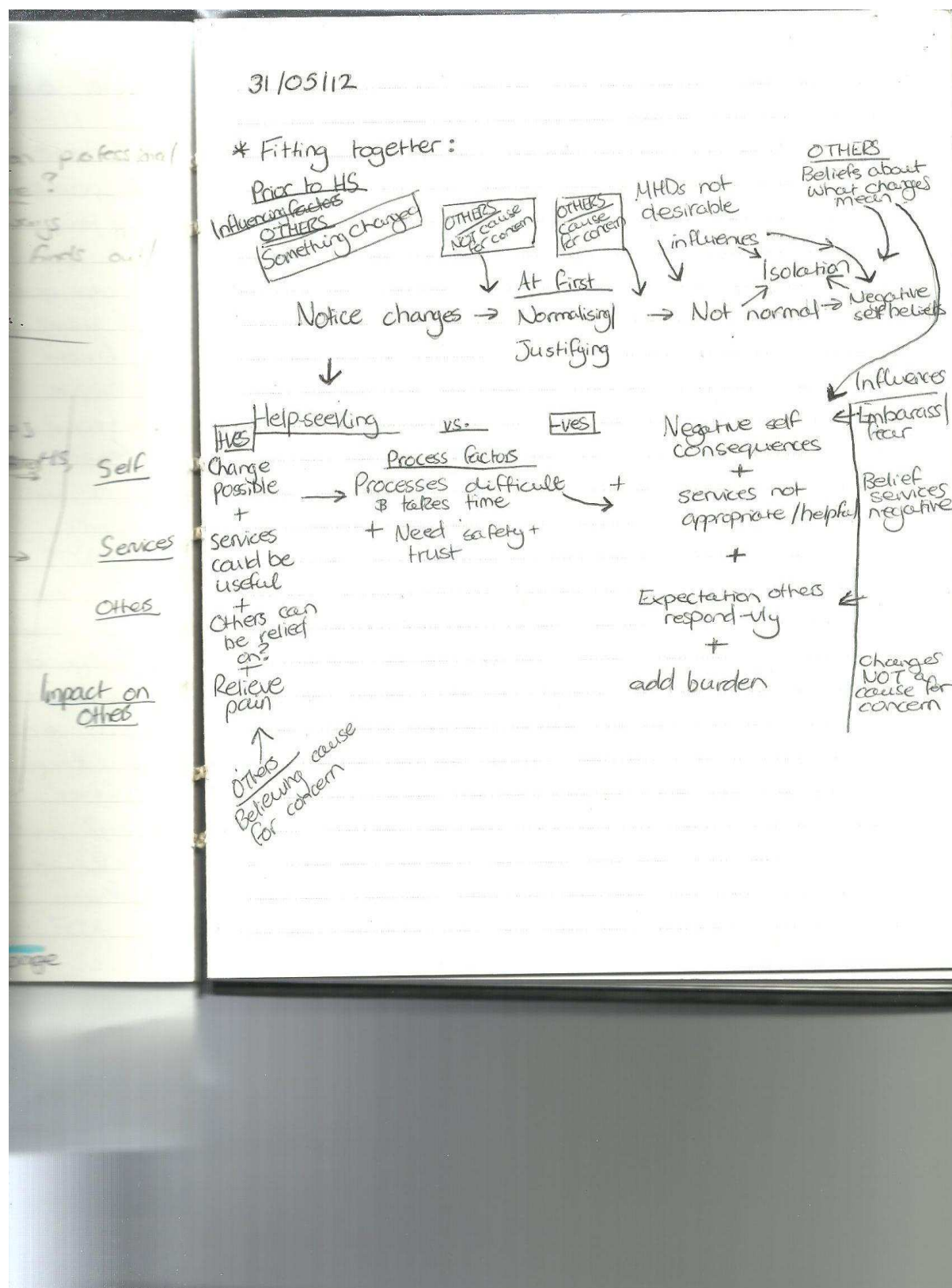
stigma literature? These views seem to be influenced by others e.g. pt 2 and his granddad feeling you should just be able to get over it, pt 5 with her dad that not wanting to be weak,illustrates the taking on of more 'societies view'. I could even extend this to pt 7, feeling broken, damaged, but had to show that he was coping at university, and pt 9, when he realised that other people didn't have these difficulties he felt weird, like an outcast. There appears to a belief that these negativities will be reinforced if you seek help.

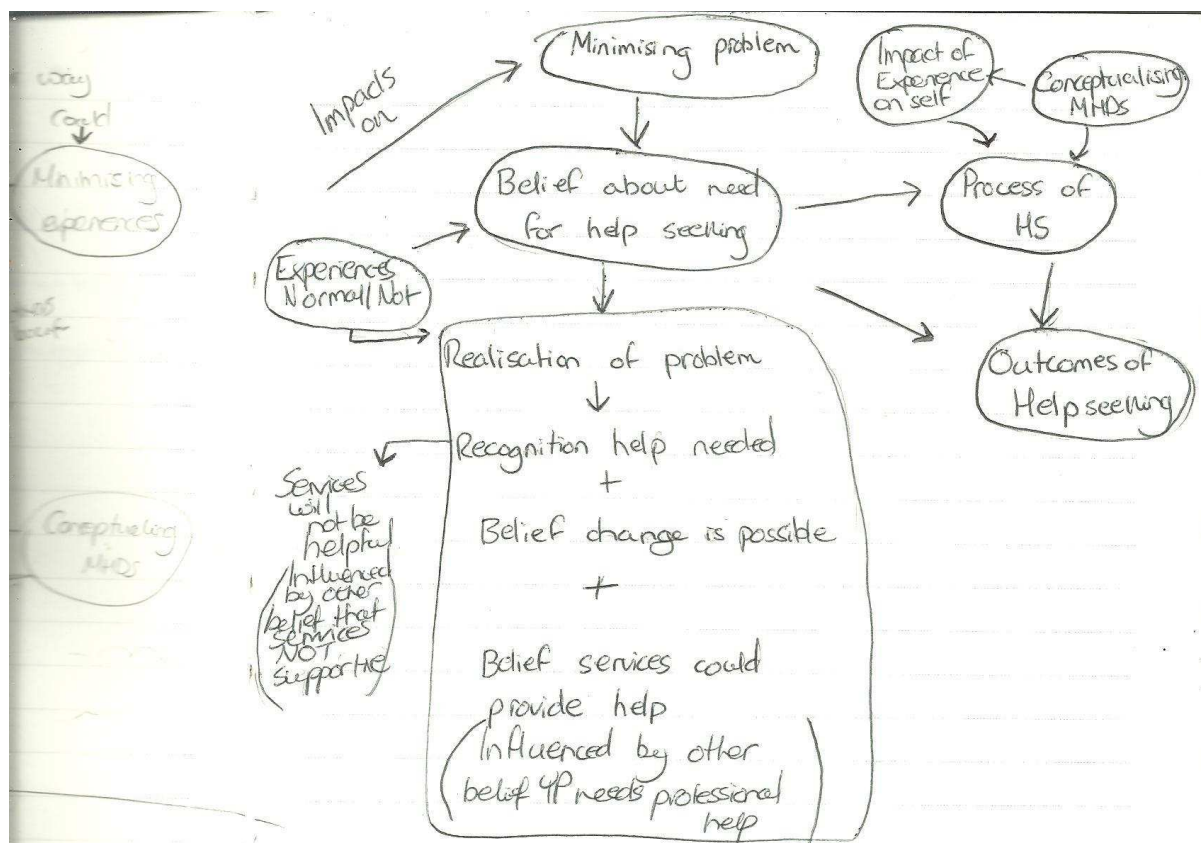
Memo 10.06.12- Developing the theory and links to previous literature

Notes linking in with previous literature:

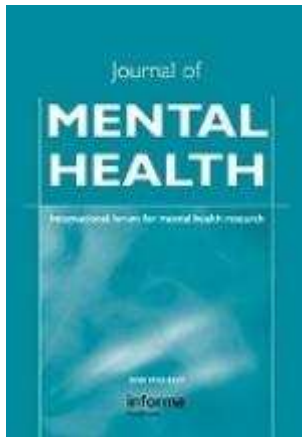
- Models of help-seeking identify recognising a 'need for help' as important in the decision making process. My categories seem important in highlighting how a need for help may be developed.
- In terms of my model, the beliefs describe the beliefs that need to be realised for a need for help to be recognised. The need and weighing up needs to be central and the other three main factors about help-seeking could feed in.
- Then you have to reach a threshold on certain aspects for beliefs about need for help to be realised.
- When beliefs about experiences not being normal reach a threshold it may not matter if the other two (process and outcome) aren't- crisis point means help will be sought, this is when other people may be implicated.
- When beliefs about MHDs affect beliefs about what experiences mean for self, can be seen as developing self-stigma and this model shows the influence that that can have on beliefs about help-seeking.
- Beliefs about MHDs could be thought about in terms of attribution theory? Whether attribute MHDs as being understandable responses to life events or whether.
- **Erikson stages.** The majority of young people experienced these changes emerging in adolescence, this is typically a time of transition and change. Erikson talks about this as time when forging between 'who one has become' and 'who society wants one to be'. This has huge implications for emerging psychosis, as previously discussed mental health difficulties are on the whole considered by society as not desirable, this is seen in the number of quotes relevant to it not being desirable, and sometimes only seen as understandable within the realms of being biological. Therefore society presumably does not want you to have a MHD. If MHDs are undesirable the preferable thing to do is attribute difficulties to something that is more 'normal'. There was an overwhelming belief in more 'normalising' explanations for both self and other. Lots of examples through the interviews that if young people have an awareness that other peoples are endorsing these beliefs than it is more likely they also will (esp.Pt2, pt3, pt5, pt9, pt12).

Appendix 13: Early model formation





Appendix 14: Publication guidelines for Journal of Mental Health



Executive Editor: **Til Wykes**

2010 Impact Factor: **0.857**

Frequency: **6 issues per year**

Instructions for Authors

Journal of Mental Health is an international journal adhering to the highest standards of anonymous, double-blind peer-review. The journal welcomes original contributions with relevance to mental health research from all parts of the world. Papers are accepted on the understanding that their contents have not previously been published or submitted elsewhere for publication in print or electronic form.

Submissions

All submissions, including book reviews, should be made online at Journal of Mental Health's Manuscript Central site at <http://mc.manuscriptcentral.com/cjmh>. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. Please note that submissions missing reviewer suggestions are likely to be unsubmitted and authors asked to add this information before resubmitting. Authors will be asked to add this information in section 4 of the on-line submission process.

The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do include the abstract, tables and references in this word count.

Manuscripts will be dealt with by the Executive Editor, Professor Til Wykes, Department of Psychology, Institute of Psychiatry, De Crespigny Park, London, SE5 8AF, United Kingdom. It is essential that authors pay attention to the guidelines to avoid unnecessary delays in the evaluation process. The names of authors should not be displayed on figures, tables or footnotes to facilitate blind reviewing.

Book Reviews. All books for reviewing should be sent directly to Martin Guha, Book Reviews Editor, Information Services & Systems, Institute of Psychiatry, KCL, De Crespigny Park, PO Box 18, London, SE5 8AF.

Manuscripts should be typed double-spaced (including references), with margins of at least 2.5cm (1 inch). The cover page (uploaded separately from the main manuscript) should show the

full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names, the exact word length of the paper and affiliations of authors and the address where the work was carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

Abstracts. The first page of the main manuscript should also show the title, together with a structured abstract of no more than 200 words, using the following headings: Background, Aims, Method, Results, Conclusions, Declaration of interest. The declaration of interest should acknowledge all financial support and any financial relationship that may pose a conflict of interest. Acknowledgement of individuals should be confined to those who contributed to the article's intellectual or technical content.

Keywords

Authors will be asked to submit key words with their article, one taken from the picklist provided to specify subject of study, and at least one other of their own choice. Text. Follow this order when typing manuscripts: Title, Authors, Affiliations, Abstract, Key Words, Main text, Appendix, References, Figures, Tables. Footnotes should be avoided where possible. The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do include the abstract, tables and references in this word count. Language should be in the style of the APA (see Publication Manual of the American Psychological Association, Fifth Edition, 2001).

Style and References. Manuscripts should be carefully prepared using the aforementioned Publication Manual of the American Psychological Association, and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes et al., 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a).

The reference list should begin on a separate page, in alphabetical order by author (showing the names of all authors), in the following standard forms, capitalisation and punctuation:

a) For journal articles (titles of journals should not be abbreviated):

Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. *Magnetic Resonance Imaging*, 18, 351–355.

b) For books:

Powell, T.J. & Enright, S.J. (1990) *Anxiety and Stress management*. London: Routledge

c) For chapters within multi-authored books:

Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In G. Parry & F. Watts (Eds.), *A Handbook of Skills and Methods in Mental Health Research* (pp. 75–89). London: Lawrence Erlbaum.

Illustrations should not be inserted in the text. All photographs, graphs and diagrams should be referred to as 'Figures' and should be numbered consecutively in the text in Arabic numerals (e.g. Figure 3). The appropriate position of each illustration should be indicated in the text. A list of captions for the figures should be submitted on a separate page, or caption should be entered where prompted on submission, and should make interpretation possible without reference to the text. Captions should include keys to symbols. It would help ensure greater accuracy in the reproduction of figures if the values used to generate them were supplied.

If the article is accepted, authors are requested to submit their final and revised version of their manuscript on disk. The disk should contain the paper saved in Microsoft Word, rich text format (RTF), or as a text or ASCII (plain) text file. The disk should be clearly labelled with the names of the author(s), title, filenames and software used. Figures should be included on the disk, in Microsoft Excel. A good quality hard copy is also required.

Proofs are supplied for checking and making essential corrections, not for general revision or alteration. Proofs should be corrected and returned within three days of receipt.

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Appendix 15: Letter and project summary of research for Research Ethics Committee



Department of Applied Psychology
Canterbury Christ Church University
Salomons Campus
Broomhill Road
Tunbridge Wells, Kent TN3 0TG

Dear [REDACTED] Research Ethics Committee

Study Title: Young People's Beliefs about Help-Seeking for First Episode Psychosis
REC reference: [REDACTED]

I am writing to inform you that this study has now been completed. Below, I have included a brief summary of the findings of this research. Please do not hesitate to contact me if you require any further information.

Yours sincerely

Helen Glossop
Trainee clinical psychologist

Title: Young People's Beliefs about Help-Seeking for First Episode Psychosis

Research context

Negative outcomes, such as low overall functioning and reduced quality of life, associated with a long duration of untreated psychosis, have been well documented (Marshall et al., 2005; Perkins, Gu, Boteva, & Lieberman, 2005). Furthermore, there is evidence that intervention in a three to five year 'critical period' after first episode psychosis can lead to positive outcomes (Birchwood, McGorry, & Jackson, 1997). Subsequently, Early Intervention for Psychosis services have grown in the UK aiming to identify symptoms earlier and improve access to effective treatment (French, Smith, Shiers, Reed & Rayne, 2010). The importance of early intervention for positive outcomes following a first episode of psychosis is recognised, however, there are still delays in young people seeking help (Brunet & Birchwood, 2010).

Research Aims

The aim of this qualitative study was to explore beliefs about help-seeking in young people who had recently experienced a first episode of psychosis, with the following questions:

- 1) How do young people's own beliefs regarding the nature of their experiences or services influence initial help-seeking for FEP?
- 2) What are young people's beliefs about others' beliefs about MHDs or help-seeking and how do these social network beliefs influence help-seeking?

Method

Twelve participants were interviewed for this study. Inclusion criteria required participants to be: aged 18 to 25, able to participate in English, and able to provide informed consent. Transcripts were analysed using grounded theory (Charmaz, 2006; Corbin & Strauss, 2008).

Results

The data showed that young people developed multiple beliefs about their experiences and about help-seeking. Three primary categories included beliefs that experiences are normal or abnormal, beliefs about the process of help-seeking, and beliefs about the outcome of help-seeking. These beliefs were considered primary because they directly linked to the development of beliefs about needing help. There were two further categories of beliefs that were important for how young people understood their beliefs about help-seeking: Existing beliefs about MHDs, and beliefs about the impact of experiences on the self. These beliefs were considered to provide a context for development of the primary beliefs about experiences and help-seeking. Young people reported that beliefs could either inhibit or promote disclosure of difficulties and help-seeking. Social networks were important to young people's beliefs about help-seeking and two primary categories of beliefs were that young peoples' perceptions of other peoples' beliefs about whether their experiences were normal, and about the outcome of seeking help, influenced their own beliefs.

Implications for clinical practice and future research

Implications for clinical interventions include a need to educate young people to recognise that they may benefit from support, as a result of the distress and impact on functioning their experiences cause, and not because their experiences are abnormal.

Further research could help clarify whether some beliefs are more central to help-seeking than others. Once identified, the most significant beliefs could form items on a measure to predict the likelihood of seeking professional support in populations that are identified as being at risk for developing psychosis.

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